

# Health Care Financing

## Extramural Report

### Medicare Hospice Benefit Program Evaluation

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Health Care Financing Administration

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## Extramural Report

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The Office of Research and Demonstrations, Health Care Financing Administration, directs more than 300 intramural and extramural research, demonstration, and evaluation projects. The projects seek alternative ways to finance, organize, and deliver health services, as well as assess the impact of Federal programs on health care costs, providers, and beneficiaries. The Health Care Financing *Extramural Report* series represents the final reports from selected extramural projects funded by the Office of Research and Demonstrations. The statements and data contained in each report are solely those of the awardee and do not express any official opinion of or endorsement by the Health Care Financing Administration.

The *Medicare Hospice Benefit Program Evaluation* describes what has been learned through 2 years (of a 3-year evaluation) about the cost-effectiveness of hospice care under the Medicare Benefit, the fairness and equity of current payment rates and the reasonableness of reim-

bursement treatment under the Benefit of certain services (such as outpatient drugs, bereavement services, and dietary counseling). It has been expected by some observers that the Hospice Benefit would be a source of savings for Medicare, substituting relatively inexpensive home care for costly inpatient care. Others have argued that the Benefit would increase reimbursements, adding home care onto relatively high levels of inpatient care for terminally ill patients. In addition, some hospice advocates have been concerned that the payment methodology and regulatory standards for Medicare-certified hospices would discourage participation. These issues are analyzed using Medicare claims and provider cost report data. Also, questions of hospice organization and structure, quality of care, quality of life, and the nature of hospice intervention are addressed, based on a review and synthesis of the relevant literature and contemporary research.

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### Medicare Hospice Benefit Program Evaluation

**U.S. Department of Health and Human Services**  
Health Care Financing Administration  
Office of Research and Demonstrations  
Baltimore, MD 21207  
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# MEDICARE HOSPICE BENEFIT PROGRAM EVALUATION SUMMARY REPORT

## EXECUTIVE SUMMARY

### 1.0 EVALUATION OBJECTIVES AND METHODOLOGIES

Congress, when passing the Medicare Hospice Benefit as part of The Tax Equity and Fiscal Responsibility Act of 1982, included a provision for automatic termination of the program in 1986 (subsequently eliminated), and a requirement that the Benefit be evaluated. The Health Care Financing Administration (HCFA) contracted with Abt Associates Inc., Jack Martin and Company and the Joint Commission on Accreditation of Hospitals (JCAH) to address three general questions:

- Is hospice care (in general, and under this or some other Medicare Benefit) cost effective?
- Are the payment rates and other requirements of this Benefit fair and equitable?
- Are certain kinds of services, such as outpatient drugs, nutritional and dietary counseling and bereavement counseling, adequately reimbursed under the Benefit?

#### Is hospice cost effective?

Cost saving under the Hospice Benefit is being addressed at two levels:

- Medicare claims data are being aggregated in 594 counties with and without certified hospices. Total Medicare Part A reimbursements, as well as inpatient and home care utilization totals, are being compared among counties over time, to see if the presence or absence of Medicare-certified hospice(s) affect costs and utilization.
- Medicare claims data are also being analyzed at the patient level, to see if comparable patients, (controlling for patient self-selection) cost the Medicare program more or less in hospice or non-hospice settings. These data will show what kinds of substitution (between home and inpatient care, between regular Medicare Part A and Benefit-reimbursed services) are associated with estimated cost patterns.

Growth and change can affect hospice cost effectiveness over time.

Three coordinated efforts have been undertaken to study the dynamics of the hospice industry.

First, JCAH has surveyed a sample of Medicare-certified and noncertified hospices, to answer specific questions regarding the structure and process of hospice care, such as:

- how are physician, dietary and nutritional, bereavement and nursing services provided in hospice?
- how are volunteers used in hospice? Are Medicare-certified hospices really different from noncertified hospices?

Second, Jack Martin and Company is collecting cost report, provider survey and patient level data from a stratified random sample of noncertified hospices, to study cost differences among hospices and reasons why hospices did not choose to be certified.

Third, in the 1988 Evaluation Report, Abt Associates will combine findings from these studies with Medicare patient claims data for the three study years to analyze cost effectiveness and fairness of the Benefit in the context of a changing hospice industry.

Are payment rates and other requirements fair and equitable?

Cost reports submitted to HCFA by Medicare-certified hospices will be combined with cost data from the Jack Martin study to evaluate the fairness of current payment rates (who wins, who loses). Alternative forms of the Benefit will be evaluated through simulations.

Data on payer equity comes primarily from findings of the HCFA hospice demonstration. These data include findings both on who pays for the direct costs of terminal illness and who pays for indirect costs (in foregone income of primary caregivers and other providers of informal care).

Are outpatient drugs, nutritional and dietary counseling and bereavement counseling adequately reimbursed under the Benefit?

This evaluation will examine the adequacy of reimbursement for these special services using data from provider cost reports. No information on patient utilization will be collected; earlier findings from the HCFA hospice demonstration will be reviewed to obtain a patient-level perspective.

Conclusion

This report presents findings from the first two years of the Benefit (FY84 and FY85). The Final Evaluation Report (Spring, 1988) will present analyses of three years of data, including new county savings analyses, cost comparisons between certified and noncertified hospices, and an evaluation of alternative reimbursement systems.

**2.0        MEDICARE AND THE U.S. HOSPICE MOVEMENT**

United States hospices have grown from a few providers in the early 1970s to an industry of over 1,200 in 1985. Growth was encouraged by changes in the way doctors and the public view death and dying, and by enthusiasm among third party payers for what appeared to be a cost effective way to care for terminally ill patients. Along with commercial insurance companies, Blue Cross Associations and state governments, the Federal government moved in the late 1970s to examine the advantages and disadvantages of formally recognizing hospice care as a package of reimbursable services.

In 1980, with the cooperation of two private foundations, the Health Care Financing Administration (HCFA) sponsored a demonstration to test the cost effectiveness of hospice care. At the same time, the National Hospice Organization (NHO) funded its own study of the advantages of hospice, and worked in Congress to secure passage of a hospice benefit for the Medicare program. By 1981, with the completion of the NHO-sponsored study and the publication of several other studies of hospice costs, Medicare hospice bills

were introduced in the House and Senate. The Hospice Benefit was passed in August, 1982 as PL 97-248, Section 122 of the Tax Equity and Fiscal Responsibility Act. After several months during which rules and regulations were written, the Benefit went into effect on November 1, 1983. A sunset provision that would have terminated the program on November 1, 1986, was eliminated by legislation on April 7, 1986.

The authors of the Hospice Benefit hoped to attain two objectives: to increase Medicare beneficiaries' access to this alternative form of care, and to help contain Medicare costs. There are several important features of the benefit:

- Election and certification. Beneficiaries must elect hospice care and receive it in a Medicare-certified hospice. By electing the Benefit, a patient waives his/her right to regular Medicare benefits, except for care not related to the terminal illness and for Part B-reimbursed care provided by attending physicians. Services are available for up to a maximum of 210 days, in two 90-day and one 30-day periods.
- Core services. Medicare-certified hospices must directly provide substantially all home health care services, including physician, nursing, medical social work and counseling services.<sup>1</sup>
- Volunteerism. Medicare-certified hospices must maintain at least a minimum level of volunteer participation.
- Interdisciplinary team. Care must be planned and managed by a team composed of physicians, nurses, medical social workers and counselors.
- Covered and noncovered services. Physical and other therapies, homemaker and home health aide services, drugs, supplies equipment, and inpatient respite care (relief for the patient's primary caregiver) are all covered services required of certified hospices; counseling services, including nutritional and bereavement counseling, are required.

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<sup>1</sup>HCFA is about to publish regulations implementing legislation that waives the core services requirements for certain rural hospices.

- Professional management responsibility. Hospices must maintain control over the care delivered to their enrollees, wherever it is provided.
- Reimbursement. Every day of service a hospice provides is reimbursed according to where the service is delivered and how intensive the care is. There are four per diem categories:<sup>1</sup>
  - routine home care, (at \$63.17 per day) which may include days with no services;
  - continuous home care (at \$15.36 per hour to a maximum \$368.67 per day) during which intensive nursing services are provided to deal with a medical crisis;
  - general inpatient care (at \$281 per day) during which a patient is institutionalized for control of pain or other symptoms of the terminal condition;
  - inpatient respite care (at \$65.33 per day) during which the patient is institutionalized to provide some relief for the primary caregiver.

Physicians who are part of the hospice staff and provide patient care are paid reasonable charges.

#### Caps and Limits

A certified hospice's annual Medicare reimbursement cannot exceed its annual Medicare caseload times a cap amount (originally set at \$6500). The cap amount for 11/1/85 to 10/1/86 was \$7391. Also, a hospice cannot be reimbursed for inpatient days (general plus respite) beyond 20 percent of the total days of care it provides in a year.

The dollar values finally used for the reimbursement limit computation, as well as the four per diem payment rates, were set through the rulemaking process and through subsequent Congressional action. In particular, Congress set the \$6500 base cap amount after the cap-setting method written into Benefit legislation turned out to produce a figure much lower than anticipated. Also, Congress set a routine home care rate of \$53.17 (now

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<sup>1</sup>These rates are consistent with Section 9123 of the Consolidated Omnibus Budget Reconciliation Act (COBRA) which added \$10 per day to each per diem, effective April 1, 1986.

\$63.17), after HCFA's rate, of \$46.25 based on information from the Medicare hospice demonstration, proved to be unacceptably low.

### **3.0        STRUCTURE AND PROCESS IN THE U.S. HOSPICE INDUSTRY**

#### **Goals and Objectives of Hospices**

Hospices try to control the pain and other symptoms of terminally ill patients in a home-like environment, while supporting both patient and family before and after the patient's death. Several features of hospice are distinctive.

- The whole family, rather than the patient alone, is the unit of care.
- Care is supervised by a team of doctors, nurses, medical social workers and counselors.
- Care is provided and monitored on a round-the-clock basis, when necessary, whether provided in an institutional setting or at home.
- Drugs and other therapies are used to prevent or control pain, rather than to cure the disease.
- Education and support are provided to patients, family and staff. Appropriate support is provided to families in bereavement.
- Volunteers play a major role in administration and delivery of care.

Most hospices serve mainly cancer patients, but on average 10 percent of hospice patients suffer from some other chronic life-threatening disease. (Only 6.3 percent of the Medicare population in certified hospices were non-cancer patients in FY85.) Many hospices stress home care, but the term "home-like" does not always mean home placement.

#### **The hospice patient**

The average Medicare beneficiary who elects the Hospice Benefit is 74 years of age, white, and a cancer victim who enrolls and remains for one to two months before dying. Not all hospice patients die in hospice: the National Hospice Study reported that nearly 10 percent of patients in the HCFA

demonstration were discharged alive. More recently under the Benefit, live discharges have accounted for 5 percent of total cases.

Research shows that knowledge of hospice is still not widespread in the population; only 40 percent surveyed in 1984 were familiar with hospice care, with men, the very elderly and individuals living in areas not served by hospices least familiar with the concept.

#### Structure of the hospice industry

Most U.S. hospices are affiliated with a hospital or a home health agency. The rest are affiliated with other institutions, particularly nursing homes, or are independent, "freestanding" programs. The average hospice is small, serving between 10 and 20 patients in a month. Medicare-certified hospices tend to be larger than noncertified hospices. Certified hospices are more likely to have restrictive admissions requirements, including the availability of someone to help provide home care (a primary caregiver), or a specified terminal prognosis from a physician than noncertified hospices. Many hospices might have a difficult time meeting the core services requirement of the Benefit; for example, many freestanding hospices have been found by JCAH to provide large amounts of home care under contract rather than directly, as required under the regulations.

#### The hospice intervention

Hospice care is not highly standardized, because there have been many schools of thought about how best to achieve goals of palliative care (pain relief) and emotional support. Drug therapy to relieve pain and control side effects has been central to the hospice approach, but experts differ on how much and what kinds of drugs to prescribe. Hospice avoids "invasive" methods, such as surgery, and the numbers of diagnostic tests and therapies other than drugs (such as chemotherapy) has been shown to be lower in hospice

than in conventional forms of treatment. Bereavement and nutritional counseling, although considered by hospice advocates to be important parts of the hospice approach, are not always used: JCAH shows that most certified and noncertified hospices offer these services, but not every family requires direct support in its time of mourning, and many hospice providers simply lack experience and knowledge in nutritional management techniques.

Process: the issue of clinical control

Maintaining continuous control over all aspects of care is critical to a successful program. Framers of the Benefit recognized this fact by requiring professional management responsibility. Yet in the past many hospices have contracted or informally arranged for care with other providers. The most common of such arrangements are for inpatient services, but some contract for home care also.

Hospice and the AIDS epidemic

Hospices face a challenge in the AIDS epidemic. The numbers of infected terminally-ill AIDS patients, the complexity of their physical symptoms, the social stigma with which others view this condition make hospices' job of education and interaction with patient and family or friends much more difficult. So far, community-based palliative care programs have succeeded where local political support and social networking have provided a foundation for coordinated action (e.g., San Francisco). Where such support is lacking, cure and care programs tend to be centered around relatively expensive hospital placement (e.g., New York).

Will the incentives in the Medicare Hospice Benefit influence the growth and composition of the hospice industry?

Although the hospice movement supported passage of the Medicare Hospice Benefit, some hospice advocates have been concerned that the Benefit will force the industry into a rigid pattern, by encouraging a traditional

"medical model" of treatment and stifling diversity and creativity. These critics argue that stressing professional management responsibility, requiring direct provision of most home care services, and placing limits on the budget and on inpatient services puts both small, community-oriented hospices and hospices oriented more toward inpatient care at a considerable disadvantage. They also see potential conflict, in the form of legal disputes between hospices and hospitals with whom they contract, over what kinds of services should be provided. However, other observers view positively any trends toward more standardization, arguing that more structure is likely to stimulate better and more consistent quality of care. Based on findings from 1985 data, the JCAH describes a "typical" Medicare-certified hospice as serving a larger caseload, with proportionately more paid, full-time, highly-qualified staff, using more techniques of planning, control and documentation than the typical noncertified hospice.

#### **4.0      IMPLEMENTATION AND OPERATION UNDER THE MEDICARE HOSPICE BENEFIT**

##### **What kinds of hospices sought certification and how many patients did they serve?**

Delays, uncertainties, changes in rates and provisions of the regulations all contributed to a slow startup of the Hospice Benefit Program. By the end of FY85, 233 hospices were fully certified. Most of the hospices that achieved certification were affiliated with another provider. Freestanding hospice programs were underrepresented, at 27 percent of the total, compared to a JCAH estimate that 33 percent of U.S. hospices are freestanding. HHA-based were the largest single group, at 47 percent of certified hospices in FY85. The average certified hospice that submitted an audited cost report in FY84 served 20 or fewer Medicare beneficiaries.

How many patients are being served?

Over 8,000 patients elected the Benefit during FY84-85. Of those hospice enrollees who died during FY 1985, 90 percent died while in hospice. Of these, 35 patients left and reentered hospice; the average "gap" between leaving and reenrolling was 55 days. The average enrollee stayed in hospice for about 32 days; only 40 stayed into the third benefit period. In comparison with previous studies, such as the National Hospice Study of the Medicare hospice demonstration, the average Benefit patient is somewhat older and more likely to be male; his stay in hospice (or at least in the Benefit) is also somewhat shorter, which may be partly due to the 210 day limit on Benefit payments to the provider.<sup>1</sup>

Where are certified hospices located?

Most certified hospices are now in the South or Midwest. In 1985, certified hospices constituted between 14 and 19 percent of all U.S. hospices, depending upon what is assumed to have been the best estimate of industry size (JCAH's estimate of 1700 or National Hospice Organization membership of 1239). Certified hospices tend to be located in relatively large, urbanized, high-income counties endowed with sophisticated medical resources that had experienced relatively rapid rates of hospital charge inflation.

What was the experience of hospices that applied for certification?

Hospices that achieved certification reported many delays and headaches along the way. These included physician hostility toward the role given to the interdisciplinary team, fear and apprehension of patients regarding "giving up" regular Medicare benefits, conflict with hospitals over local market shares, and intermediary payment delays.

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<sup>1</sup>Certified hospices are not allowed to discontinue services to Medicare Hospice Beneficiaries after the 210 Benefit days.

Who Pays for Hospice Care?

Even though prior studies have indicated that hospices save on the overall costs of care, some of the parties responsible for payment might find their contribution to hospice payments more expensive than conventional care. For example, families might face higher out-of-pocket expenses when a patient stays in the home, so that a home-oriented strategy effectively "shifts" the burden of payment from a public or private third party onto family.

A 1979 GAO study showed that nearly one-third of hospices' operating revenues came from self-paying patients, commercial insurance and philanthropic contributions. JCAH found that this was still true for noncertified hospices, but that Medicare-certified hospices relied heavily on Benefit and regular Part A reimbursement. In HCFA's hospice demonstration, patients spent nearly \$5 per day out-of-pocket for all medical expenses. This was much less than conventional care patients, who spent about \$46 per day. In addition to out-of-pocket expenditures, hospice families often had to give up sources of income in order to care for the dying patient. The NHS estimated that primary caregivers devoted about 10 to 14 hours a day to providing direct care. This outlay of time and effort was particularly heavy among caregivers of patients in home care-based hospices. The average caregiver who quit work to be with the patient gave up about \$2,400 in lost income. Combined with an average of \$1,377 in direct out-of-pocket expense, the average family of a demonstration hospice patient incurred over \$3700 in direct and indirect costs, over half of the total reimbursed costs of hospice care.

### Is hospice less expensive than conventional care?

An extensive literature review conducted for the Hospice Benefit Evaluation shows that most previous studies of hospice and conventional means of caring for the terminally ill have agreed that hospice is no more expensive than conventional care; in many cases, it appears to be considerably less expensive (see Mor *et al.*, 1985, Section 9.0). Although it is hard to compare these studies because they defined costs and service characteristics differently, findings are fairly consistent.

Total costs per day in hospice have generally ranged between \$75 and \$120, or about \$3,000 to \$6,000 per case. Medicare reimbursements for Benefit patients averaged \$3,090 in FY85. Costs per day are higher for hospice patients in one or all of the following categories: relatively severe physical impairment at enrollment, little to no home support, a cancer diagnosis or enrollment in a hospice that provides direct inpatient care. Longer hospice stays are more costly overall, even though the costs per day are generally lower than they are for shorter stays (Mor, *et al.*, 1984).

### Evidence on how hospice and conventional care compare among cost components

Although it is hard to compare conventional care to hospice because there is no clear point at which conventional care "starts" as there is with hospice enrollment, studies have pointed out several services in which costs differ:

Inpatient services. Hospice inpatient costs have generally been lower than conventional care, because hospice patients stayed fewer days in inpatient settings. This has been particularly true for hospices that provided no direct inpatient care. Ancillary costs have also been lower in hospice than in conventional care.

Home care services. One source of hospice saving in the past has been the extensive use in hospices of home services rather than inpatient services. However, in bedded hospices that participated in the HCFA demonstration, home services were apparently added to high levels of inpatient care, rather than substituting for them, as was apparently the case in non-bedded hospices.

Nursing home services. The available evidence indicates that neither hospice nor conventional care patients use nursing home services intensively; this category averages less than 3 percent of total costs in the last year of life. Medicaid nursing home reimbursements were 12 percent of total reimbursements (Medicare payments were 0.6 percent) for jointly eligible, terminally ill beneficiaries.

Physician services. Conventional care patients spend nearly twice as much on physician services as hospice patients. This is partly due to the fact that most physician care is provided in inpatient settings.

Outpatient drugs, supplies and equipment. Limited evidence indicates that conventional care patients spend less on outpatient drugs, compared to hospice patients.

Costs and Medicare Reimbursements to Hospice Benefit and Conventional Care Patients: How much did Medicare spend on Hospice Benefit enrollees in the last two years of life?

Based on data from the 6,292 Benefit patients with complete claims data who died in FY84 or 85, average Benefit reimbursements per enrolled patient increased from FY84 to FY85 by 16 percent (from \$1,798 to \$2,078), a rate considerably above the 6.2 percent increase in the medical care component of the consumer price index. Over the same period, regular Part A payments per Beneficiary declined slightly in the months before Hospice Benefit enrollment, but increased in the enrollment period.

How do Hospice Benefit charges vary across hospice types?

Average charges<sup>1</sup> in provider-based hospices were higher than in freestanding hospices in both FY84 and 85. None of the Medicare-certified hospices had any difficulty operating within the Medicare reimbursement cap.

HHA-based certified hospices' charges declined by 11 percent from FY84 to FY85, due, in part, to reduced relative use of expensive continuous home care and general inpatient care and more use of routine home care. Next year's report will try to examine reasons for such trends, using data from three years' experience under the Benefit.

How much does the Hospice Benefit cost in comparison to conventional care?

A straightforward comparison of Benefit patients who died in FY85 with 7,467 non-hospice Medicare-reimbursed cancer patients who died in the same year shows that hospice patients incurred \$420 less in Medicare reimbursements over the last year of life. Most of the difference reflects lower relative reimbursements to Benefit enrollees in the last month of life; in fact, Beneficiaries enrolled two or more months from death incurred reimbursements higher than conventional care patients in the earlier months.

How do components of Medicare reimbursements for hospice and conventional care differ?

Up to the last month of life, average Beneficiary inpatient utilization slightly exceeded conventional care averages. In the last month, conventional care inpatient reimbursements grew to twice the level of hospice inpatient reimbursements.

Total home care reimbursements were higher for Benefit enrollees in every month, both before and during enrollment, with strong evidence that home

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<sup>1</sup>Hospice charges and reimbursements vary similarly among hospice types. Charges were used in this analysis, because reimbursements were not recorded on many hard copy hospice claims during FY84.

services substituted for regular Part A and Benefit-reimbursed hospital services in the last month of life.

Medicare-certified hospices have generally been in compliance with the 20 percent cap on Benefit-reimbursed inpatient days. Two out of 5 SNF-based hospices exceeded the inpatient limit in FY85, compared to 5 of 63 among freestanding, 8 of 39 hospital-based and 4 of 63 HHA-based.

#### Other Hospice Benefit expenses: physician services

Charges for Benefit-reimbursed physician services dropped from two to one percent of total Benefit charges between FY84 and FY85. Preliminary indications are that few Beneficiaries submitted Part B physician claims for services during hospice enrollment. A complete analysis of Part B claims of hospice and conventional care patients will be included in the final Evaluation Report.

#### **6.0        THE MEDICARE HOSPICE BENEFIT: IS IT COST EFFECTIVE AND EQUITABLE?**

This report presents findings, from a preliminary test based on FY85 data, that the Medicare Hospice Benefit has probably been a source of cost saving for Medicare.

##### How Much Does Hospice Save Over Conventional Care?

##### Evidence from Prior Research

The NHS found that conventional care costs exceeded costs of hospice in the HCFA demonstration by over 100 percent in the last month of life. Most studies show cost savings, ranging from near zero to over double the cost of conventional care depending on what costs are counted, how long the enrollment periods evaluated are and what kinds of patients are compared. Average savings have differed by type of hospice (non-bedded hospice savings in the NHS were larger than savings for bedded hospice patients). However, patient characteristics (age, sex, diagnosis) had little apparent effect on the size of hospice savings.

### Early Estimates of Cost Savings Under the Benefit

Despite past evidence of hospice savings, some suspect that the current Hospice Benefit might not save Medicare any money. Two views of this issue were expressed during the course of policy development. The Congressional Budget Office (CBO) predicted that, by saving extensively on payments for hospitalization, the Benefit would save the Medicare program nearly \$71 million by 1987. In contrast, the Administration (HCFA, Office of the Actuary) argued that savings in hospitalization would be less than the CBO estimated, and that with the additional home care and other expenses of hospice, the Benefit program would add \$160 million in costs by 1987. The reasons for these differences are complex. They are partly due to different assumptions about how Medicare pays for hospitalization. Under the new Prospective Payment System, Medicare pays a flat rate for a single admission, rather than pay for per diem costs. CBO's recent revision of its predictions, based on the new PPS methodology, shows a much more modest expected saving (\$4 million in 1987, compared to its original estimate of \$7 million). Using more recent information from the HCFA demonstration, HCFA/OACT has also revised its predictions of the excess costs of the Benefit, from \$0.64 saved for every dollar spent on the Benefit to \$0.52.

### Have Estimated Hospice Savings Been Based on the Wrong Kinds of Patient Comparisons?

Part of the reason why some feel that the Benefit will not yield savings is caused by skepticism over cost comparisons in previous studies. It is argued that research that demonstrated hospice savings compared apples and oranges, by selecting conventional care patients who were particularly heavy users of reimbursable medical services and comparing them to hospice patients, who tend, even before entering hospice, to be light users of these services. In fact, there is evidence that there are Medicare beneficiaries whose use of

formal care is minimal, and who might be attracted to use more services under the Benefit. Forty-three percent of conventional care cancer patients sampled for this Evaluation died outside a hospital. Their Medicare-reimbursed expenditures in the last year of life were \$17,100, compared to a sample average of \$20,756. HCFA studies, based on National Center for Health Statistics data, suggest that the percentage of all patients who die at home is increasing.

#### The Hospice Benefit Evaluation Methodology

The Medicare Hospice Benefit Evaluation is attempting to control for the effects of patient self-selection by randomly sampling conventional care patients with at least one cancer or life-threatening non-cancer hospital claim in the two years before death, from counties with and without hospices, and by applying two methodologies to compute savings.:

- an actuarial approach, that superimposes average hospice utilization patterns on a sample of conventional care patients, to determine how much would have been saved in conventional care reimbursements had these patients been enrolled in the Hospice Benefit. This general approach was used by HCFA/OACT in its projections of the cost impact of the Benefit on the Medicare Trust Fund.
- a statistical approach, that addresses essentially the same question, using a statistical regression that controls for patient self-selection effects. This approach was used in the National Hospice Study, to evaluate data from the HCFA hospice demonstration.

A preliminary test of the Medicare savings hypothesis, based on the actuarial approach, has been conducted using FY85 conventional care and Hospice Benefit patient claims data. It shows that, under two separate assumptions regarding how many non-hospice hospital admissions would be saved, the Benefit generated either small net costs (\$0.96 saved for every dollar spent) for enrollments of 30 days or less, or fairly substantial savings (\$1.36 saved for every dollar spent). Savings potential was associated with

provider affiliation. Freestanding and HHA-based hospices generated savings, or were cost-neutral relative to conventional care. Savings estimates for patients enrolled 30 or fewer days in hospice ranged from \$0.99 for every hospice dollar spent (HHA-based hospices) to \$1.43. Hospital- and SNF-based hospices did not generate savings, under most of the assumptions used in this study; estimates ranged from \$0.77 for every dollar spent on SNF-based hospice patients to \$1.29 for hospital-based patients. These findings will be re-tested, using both the actuarial and statistical methodologies applied to three full years of data, in next year's Final Evaluation Report.

**Are Hospices Effective at Achieving Clinical and Other Goals?**

Previous studies have shown that hospices are at least as effective (and sometimes more so) as conventional care in achieving goals of pain and symptom relief, family and staff support.

**Pain and symptom control.** Hospices treat chronic pain with a mixture of drug and other therapies. Research shows that pain relief is somewhat more effective in an inpatient setting than at home, partly because it is difficult for hospice staff to train and monitor the activities of primary caregivers. Counseling aimed at improving patients' overall sense of well-being has been most effective when programs are targeted toward specific goals.

**Family counseling.** Although there is no hard evidence that hospices deal more effectively with families' counseling needs before the patients' death, there is evidence that hospices do address families' needs during the period of bereavement after death. However, there is no "standard" approach to providing bereavement support. Hospices recognize, and research agrees, that some families require no support.

Staff support. Paid and volunteer hospice staff face emotionally draining duties that can produce depression and burnout. However, research shows that hospices that address issues of staff morale and provide for continuing education and support which can effectively reduce burn out and staff turnover. Hospice also has rewards for nurses, who gain a greater measure of autonomy in the hospice environment than they enjoy with more traditional health care providers.

Are Payment Rates and Conditions Under the Benefit Fair and Equitable?

Critics of the Benefit have charged that the per diem payment rates are too low, that the Benefit favors hospices that are particularly efficient in providing home care, and that the payment methodology fails to cover adequately certain services, such as outpatient drugs, dietary and nutritional counseling and bereavement counseling. This report addresses these issues, using data from 36 Medicare-certified hospices that submitted reliable FY84 cost reports.

The Routine Home Care Rate

Congress raised the routine home care rate that was set in the Final Rules (\$46.25) twice, first to \$53.17 effective October 1, 1984, and then to \$63.17, effective on April 1, 1986. Critics had contended both that the overall rate was too low to pay hospices for the intensive home services that they deliver and that the drug component is inadequate. The National Hospice Organization estimated that the average home day costs a hospice about \$70 in 1984. Estimates from the literature had shown costs ranging between \$46 and \$58. In FY84, 18 hospices incurred per diem costs below the \$53 rate, and 18 incurred higher costs.

### Inpatient Care Rates

Research shows that general inpatient costs in hospice have ranged from \$177 to \$523 per day. Much depended on whether or not a hospice provided care directly or must arrange for it. Contracted care is generally more costly than directly provided services. The National Hospice Organization estimated that an average inpatient day cost \$368 in 1984, compared to the payment rate of \$271. In FY84, over half of the certified hospices that had audited cost reports showed costs exceeding the \$271 rate. This percentage was not markedly changed by adding \$10 to the rate.

### Continuous Home Care Rates

The continuous home care rate was set at \$14.94, payable for a minimum of 8 hours, up to a maximum payment of \$358.67. At this rate, 18 hours of continuous care is equivalent to one general inpatient day. However, there are reasons why hospices might prefer to prescribe continuous home care for crisis situations: the patient can continue to be supported in a home environment, and the amount of continuous care is not capped under the Benefit as inpatient care is. The National Hospice Organization estimates that continuous care actually cost \$466.56 per day, which might deter use if this figure is correct. Of those that used continuous care, most certified hospices incurred costs above the maximum daily rate in FY84.

### Does the Current Legislation Favor One Type of Hospice Over Another?

Critics have argued that the core services requirement, the budget cap and the inpatient day limit combine to favor hospices that have a comparative advantage in servicing patients at home. The legislative increases in all rates by a flat \$10 per day adds strength to the alleged "home bias" in the Benefit because the largest percentage increase (about 19 percent) applies to the routine home care rate. However, it is too soon to conclude, as some

have argued, that HHA-based programs benefit most under the Benefit. In some respects, the Benefit favors hospices with inpatient capacity. By requiring all certified hospice programs to contract for and manage inpatient care, the Benefit may force HHA-based hospices to absorb losses in markets where the only available sources of contract case are costly hospitals.

Are Certain Service Categories Appropriately Reimbursed Under the Benefit?

Congress identified three services for special examination in the evaluation of the Hospice Benefit: outpatient drugs, dietary and nutritional counseling and bereavement counseling.

Outpatient Drugs

Outpatient drug costs that certified hospices incur are reimbursed as part of the routine and continuous home care rates. Hospices are permitted to collect a 5 percent copayment on drugs from beneficiaries, although they need not do so. The drug component of the routine home care rate, adjusted downward for the copayment, is \$0.95 per day, or about \$32 per stay. Average reported outpatient drug costs in 31 certified hospices in FY84 were highest in HHA-based hospices (\$5.79 per day) and lowest in hospital-based hospices (\$1.21 per day).

Levels of drug utilization among HCFA demonstration hospice patients varied. Most receive prescriptions for pain-controlling drugs (between 60 and 90 percent, depending on the type of hospice program), even though not all patients used these prescriptions. Many fewer received drugs for other symptoms; for example, under 5 percent of the demonstration hospice patients received drugs to relieve depression. Observers have worried that the Medicare drug payment is too low and too inflexible to take account of the variation in needs among patients.

Data from the HCFA demonstration do show that patients, in all types of hospice programs, spent as much as \$1.31 per day out-of-pocket to supplement drug costs reimbursed by Medicare and other payers.

Since the average hospice patient in the HCFA demonstration would have been liable for a total copayment of under \$40 under the new Benefit, it seems highly unlikely that the copayment requirement will seriously deter appropriate drug utilization.

#### Dietary and Nutritional Counseling

Dietary and nutritional counseling services are designed to help patients control disease symptoms by controlling their diets, to prescribe techniques such as intensive intravenous feeding when necessary, and to help families adjust emotionally to the changes in patients' dietary needs. Few demonstration hospices had experience with this service. Only 4 out of 25 HCFA demonstration hospices submitted bills for dietary counseling. In FY84, 3 out of 36 certified hospices reported dietary costs. Therefore, it is too soon to tell whether or not the Benefit's requirement that counseling be provided, but not paid separately from the per diem rates, is unfair.

#### Bereavement Counseling

Certified hospices have to provide bereavement support, but they cannot be reimbursed for it because the "beneficiary" of this support (the bereaved family) is not entitled under Medicare to direct services after the patient dies. Many hospices use volunteers to assist with bereavement support. Methods of helping families vary widely. Some use home visits, often provided by a nurse who provides emotional support and assesses family needs. Others organize group therapy sessions or social functions. Many families neither receive nor need direct support. Bereavement costs averaged \$80 per case in certified hospices during FY84. However, total spending on

bereavement counseling was under one percent of total expenses across all types of certified hospice. Therefore, until more data on hospice costs under the Benefit are available, there is no reason to suggest a change in standards regarding bereavement counseling.

#### Conclusion

Critics have argued that Medicare payment rates are so low and standards so restrictive that many hospices simply cannot afford to participate. They point to the fact that the largest category of certified hospices in the first and second years has been HHA-based, the type of program supposedly most capable of providing care inexpensively in a home setting. This conclusion is premature, however. In an industry as dynamic as hospice the participation patterns that appear during program implementation do not necessarily show a trend for the future. Participation rates are bound to be affected by events outside of the industry. Medicare's Prospective Payment System, which has allegedly encouraged hospitals to discharge some patients prematurely to avoid financial loss, might encourage hospitals either to enter into more contractual agreements with hospices and other aftercare providers or to enter that market themselves.

Preliminary findings suggest that some types of hospices (freestanding and HHA-based programs) have generated savings for Medicare. Under certain assumptions, hospice care as a whole seems to save Medicare reimbursement for most patients. However, this and previous studies that show hospice to be cost effective must be used cautiously, because the Benefit creates a new set of rules and incentives that may, in the long run, affect both cost and quality of care. Patients who would previously have used few Medicare reimbursable services might be attracted to use the Benefit. Also,

the high-cost stereotype of conventional care may be changing, as patients outside hospice demand options other than aggressive, curative care.

The Final Evaluation Report, due in 1988, will draw together three years of data (FY84-86) from patient claims and from Medicare-certified and noncertified hospice cost reports, to produce a full analysis of the Benefit's cost saving potential and fairness, under the current system and under alternative reimbursement models.

## EVALUATION OBJECTIVES AND METHODOLOGIES

The Medicare Hospice Benefit, enacted as part of the Tax Equity and Fiscal Responsibility Act of 1982, received bipartisan support in both Houses of Congress. However, the legislation balances Congressional enthusiasm for hospice with programmatic conservatism. The feeling that the government might be "going out on a limb" by offering this benefit in a new, evolving area of health care led Congress to include two special provisions in the Benefit legislation:

- A "sunset" provision, calling for termination of the Benefit in November, 1986, which Congress subsequently eliminated;
- A requirement that the Benefit be evaluated.

Within DHHS, the Health Care Financing Administration (HCFA) has responsibility for administering the evaluation effort and for reporting to Congress. HCFA chose to conduct this evaluation over a three-year period, through several related contracts. The principal contractors include:

- Abt Associates, Inc. which, along with subcontractors Brown University and SysteMetrics, Inc., are responsible for conducting a cost effectiveness analysis and evaluating the fairness of the current system using both a coordinated synthesis of the literature on hospice and terminal illness and original analyses of Medicare and Medicaid data.
- Jack Martin and Company, which is gathering and analyzing cost and utilization data from approximately 100 hospices not certified to provide care under the Benefit.
- The Joint Commission on Accreditation of Hospitals (JCAH), which has collected and analyzed information on structure and process of care in certified and noncertified hospices.

Congress requested answers to three general questions:

- Is hospice care cost effective? In particular, is hospice care under this or some alternative Medicare benefit cost effective?
- Are the payment rates and other requirements of this Benefit fair and equitable?
- Are certain kinds of services, such as outpatient drugs, nutritional and dietary counseling and bereavement counseling adequately reimbursed under the Benefit?

The evaluation team is implementing an analysis plan that operates at several levels to achieve project objectives. Medicare and Medicaid claims will be used, both to study costs of care at the patient level and to measure aggregate Medicare expenditures at the county level. Issues of rate fairness and equity will be addressed with information from cost reports. The major sources of data for the evaluation are listed in Table 1.

### 1.1      Is Hospice Cost Effective?

Cost savings under the Benefit is being measured in two ways.

First, total Medicare regular Part A and Benefit payments for treating terminally ill patients during the last year of life will be compared at the county level, between areas served by hospices (certified and noncertified) and areas without hospice care. The evaluation will work with data from a county sample, made up of 584 counties in FY84, including:

- 125 counties with one or more certified hospice;
- 212 counties with one or more noncertified hospices, but no certified program; this was one-third of all counties with hospice programs in the first year (FY84); and
- 247 counties with no hospice programs.

This sample will be augmented in the succeeding years of the evaluation.

By comparing total payments at the county level, over time and across counties with differing percentages of care delivered in certified and noncertified hospice programs and nonhospice settings, it should be possible to identify major Benefit effects on Medicare program costs. This kind of analysis has the advantage of showing how both the relative efficiency of currently certified hospices and changes in numbers and types of hospice providers affect Medicare expenditures. Its major disadvantage is that it tends to hide the many conflicting patient-level influences on hospice and nonhospice expenditures.

Table 1

**Medicare Hospice Benefit Program Evaluation**  
**Major Data Sources and Evaluation Tasks**

| Data Sources  | Tasks |                        |                      |
|---|-------|------------------------|----------------------|
|   | Cost  | Fairness<br>and Equity | Specific<br>Services |
| Effectiveness   |       |                        |                      |
| Medicare Hospice Benefit Enrollment Files                             | X     |                        |                      |
| Medicare Hospice Claims/<br>Bill History File/<br>Part B Claims Tapes | X     |                        |                      |
| Medicaid Tape-to-Tape<br>Files (New York and Michigan)                | X     | X                      | X                    |
| Medicare-Certified Hospice Cost Reports                               |       | X                      | X                    |
| Noncertified Hospice Cost Reports                                     |       | X                      | X                    |
| JCAH Hospice Survey   | X     |                        | X                    |
| National Hospice Study Data Base                                      | X     |                        | X                    |
| Research Literature on<br>Hospice and Terminal Illness                | X     |                        | X                    |

A complementary approach, using patient-level information, is being employed to counter this disadvantage. Hospice and nonhospice patients from the 594 sample counties have been selected for comparisons across measures such as inpatient admissions and days and home care utilization. Several detailed questions are being addressed with these data:

- Were costs and utilization patterns of patients who exercised their option under the Benefit to switch hospice programs different from patterns of patients who did not switch?
- What were Medicare expenditures during hospice and after discharge for patients who were discharged alive from hospice?
- Did hospice savings vary by type and patient (age, sex, principal diagnosis, level and pattern of utilization before enrollment, the type of hospice in which care was received)?
- How did savings attributable to hospice vary with length of stay in the program?
- What determined patient/family election of hospice (certified or noncertified) given patient characteristics and the availability of hospice and nonhospice alternatives?
- For what kinds of Medicare reimbursable services did the Hospice Benefit substitute?
- How does the level and intensity of utilization, by type of service, differ between certified hospice patients and patients in other settings?
- Is there evidence that home care is substituted for inpatient care to a greater extent among certified hospice patients than among patients in other settings?

Approaching the question of hospice savings at both patient and area levels should help document major changes in aggregate Medicare spending related to the Benefit and describe how savings might be related to characteristics of patients enrolled in hospice programs. Dealing with the problem of selection bias will be a major objective of the evaluation. Since patient enrollment in the Benefit is not random, a way must be found to show how much hospice saves for all types of potential patients, including those predisposed both to very high and very low utilization. The patient-level

analysis has sampled nonhospice patients to provide a broad enough range of utilization experience for these comparisons.

The dynamics of the hospice industry and the environment within which it operates are also being addressed. There are several tasks in the evaluation that will describe how this system is changing and draw conclusions about what these changes could mean for cost effectiveness.

First, the JCAH survey has described hospices and the nature of the hospice intervention. JCAH has addressed the following questions:

- What is hospice care? What are the range and types of services hospices offer? Who provides care, and what are their qualifications? How are hospices, by type of program, distributed across the nation?
- How are hospices coordinating care?
- What is the nature of the primary physician's involvement in hospice care?
- What are the primary interventions for symptom control?
- What policies and practices exist regarding feeding and other treatment issues?
- What ancillary services are used?
- What is the frequency and distribution of types of nursing treatments?
- What bereavement, nutritional and dietary counseling services are being provided?
- What roles are volunteers filling in providing hospice care? Are the usage patterns of volunteers different between certified and noncertified hospice providers? Is the Medicare requirement for volunteer use appropriate?
- Has the nature of hospice care changed since the advent of Medicare financing? Have the roles and use of volunteers changed since the inception of the Medicare Benefit?
- Are Medicare-certified hospice providers different from non-Medicare hospice providers?

Second, Jack Martin and Company is collecting information from noncertified hospices that is similar to data submitted in cost reports by

Medicare-certified hospices. These data will help answer the question of how certified hospice providers might be "different." In addition, this study will examine reasons why noncertified providers did not choose to seek certification.

Third, in the final report of the Hospice Benefit Evaluation, due in 1988, Abt Associates will use information from the above two studies, plus data from Medicare-certified hospice cost reports to describe the dynamics of change in structure, process, costs, and utilization patterns in the hospice industry under the Benefit. Although it will not be possible to determine precisely how much the Benefit affected these changes, it will be possible to describe patterns of change across areas and hospice types, between counties that experienced hospice expansion and those that did not.

#### 1.2 Are Payment Rates and Other Requirements Fair and Equitable?

Congress never spelled out what "fair and equitable" means in the context of the Benefit, but there are two plausible interpretations that will be used. The first is rate fairness: do the payment rates cover hospices' costs of providing services? The second is payer equity: is the burden of paying for hospice services equitably distributed?

Several specific questions about rate fairness will be addressed:

- Are the per diem rates too low? Should the relative level of the four rates be changed?
- Is the budget cap a serious restriction?
- Is the inpatient limit a serious restriction?
- Do other provisions in the Benefit hurt currently certified hospices and keep others out of the program: e.g., requirements for core services, maintenance of professional responsibility, interdisciplinary team standards.
- What would be the implications of changing rates or requirements?

Most of the evaluation of rate fairness will be based on data from cost reports submitted by certified providers. In the second year of the study, cost data from noncertified providers is becoming available; these, together with certified hospices' reports, will form the basis for a comparison of operating costs by certification status. Information from the JCAH and Jack Martin studies will document the reasons hospices did not seek certification as well as characteristics of noncertified hospices (such as extensive use of contracted inpatient or home care) that might have influenced this decision. The question of alternative ways to structure the Benefit will be dealt with in the final year of the evaluation; data from surveys, from patient and provider-level files, and from previous research will be used to test the effects of changes in the Benefit on Medicare payments, costs of care, utilization and provider participation. Some preliminary work has been done in this area, testing the implications for hospices' Medicare revenues of using patient mix information to adjust the per diem payment rate.

A complete assessment of payer equity involves value judgments. Who should pay for hospice cannot be evaluated in a political vacuum. Congress intended that Medicare should pay "most" of the costs of its terminally ill beneficiaries who elect the Benefit. However, several exceptions were made, some explicit and some implicit. Cost sharing by the family was allowed (not required) for outpatient drugs and inpatient respite care. The costs of treating any conditions not related to the terminal illness were not to be reimbursed under the Benefit; Medicare might pay them under its regular program or other payers might pick up the bill.

This evaluation will analyze payer shares of hospice costs. Questions that we shall address include:

- Are out-of-pocket expenditures higher for Medicare hospice patients than for patients in other programs?
- What portion of the average cost of outpatient drugs to Medicare hospice patients pay, compared to patients in other settings?
- What are the charges and payments per unit of service, in hospice and other settings, by payer?

Many of these analyses use data from previous research, such as the National Hospice Study, because the evaluation scope of work does not call for any new data collection on payers other than Medicare and Medicaid. Medicaid payment issues have been handled through analysis of data on terminally ill Medicaid patients in Michigan and New York; although no explicit comparison between hospice and nonhospice Medicaid patients will be made, this analysis provides a base of information on overall patterns of care. In addition, Medicare and Medicaid data for a sample of patients with joint eligibility have been merged. These data show how much of a terminally ill patient's care in the last year of life is paid for by the two programs.

### 1.3        Are Outpatient Drugs, Nutritional and Dietary Counseling and Bereavement Counseling Adequately Reimbursed Under the Benefit?

Congress singled out these services for special treatment in the evaluation. Each poses a unique set of issues.

Outpatient drugs. Outpatient drugs are reimbursed through the routine and continuous care home care rates. Hospices can collect a copayment, if they file a price list of drugs with their intermediary. Concerns about drug reimbursements have centered on adequacy: given the great variability in drug utilization among patients, are hospices adequately paid at a rate of \$0.95 per day (the drug component of the routine home care rate)? Some observers have also worried that if hospices were to collect the copayment, patients and their families might be discouraged from using appropriate amounts of medication. These concerns are being studied primarily

with data from provider cost reports; there are no plans to collect such data from patients, and drug utilization is not separately reported in the Benefit claims. As baseline information, data on outpatient drug utilization and charges among patients who participated in the National Hospice Study have been analyzed, to see what patient and hospice characteristics were associated with different patterns of drug use.

Nutritional and dietary counseling. This service is not separately reimbursed under the Benefit. Evidence from the HCFA demonstration also seems to indicate that it has not been provided, in a formalized manner, by many hospices. The objective here will be to use cost reports to describe costs allocated for nutritional services. Information the JCAH collects in its survey documents qualifications of service providers and the nature of hospice nutritional programs.

Bereavement counseling. To be eligible for certification, a hospice must provide for bereavement support; however, it cannot be reimbursed for providing bereavement services, because the family is not a Medicare beneficiary. Here too, the principal focus will be on data from cost reports, supplemented with recent information on hospice practices in providing bereavement services from the JCAH survey.

#### 1.4        Conclusion

This evaluation combines knowledge gained in previous research with analyses directed explicitly toward effects of the Medicare Hospice Benefit. Part of this effort has been a review and synthesis of the literature on hospice care and terminal illness, compiled by Brown University. This review provides baseline information in the first year of the evaluation (See Mor, et. al. Hospice Care: A Comprehensive Review of the Literature, 1985). As the study progresses, more current information has become available on how the

Benefit has worked. Chapters on state hospice legislation and on the challenge that AIDS poses to the hospice movement were added to the second-year literature review.

This report presents information on implementation and growth of the Benefit program over a two year period (FY84 and 85). Estimates of total charges, Medicare payments, lengths of enrollment and utilization of Hospice Beneficiaries are presented. Preliminary estimates of hospice saving, based on Benefit and Part A payments for Benefit enrollees and a comparison sample of conventional care patients, are presented. Analyses of per diem rates and costs of specific services (drugs, bereavement and dietary counseling), based on FY84 certified hospice cost reports, are reported. JCAH findings regarding structure and process in certified and non-certified hospices are discussed. Supplementary information from research reviewed during the first two study years is included, where appropriate, for comparison with Benefit outcomes and for completeness, in areas not fully covered in the evaluation.

Not all of the evaluation issues discussed here have been examined thoroughly to date. These include:

- County level savings analyses;
- Cost comparisons between certified and noncertified hospices;
- Evaluation of alternative reimbursement systems.

The final report (Spring, 1988) will address these and the other evaluation questions, using data from all three years of the study (FY84-FY86).

**2.0      MEDICARE AND THE U.S. HOSPICE MOVEMENT**

**2.1      Social and Political Context: Hospice and the High Cost of Dying**

In the short period since a few hospices began serving patients in the early 1970s, the hospice movement has spread throughout the United States in an increasingly favorable social and political environment. Changing attitudes toward death and dying have paved the way for hospice. Well-publicized instances in which patients and their families challenged the assumptions behind aggressive, curative therapies demonstrated a growing belief that an incurably ill patient's choice to die with dignity should be honored.

Coincident with this shift in public awareness and attitudes, the Federal government began to search for ways to reduce costs of serving Medicare beneficiaries. Lubitz and his colleagues (1984) showed that, although only about 6 percent of Medicare beneficiaries die in any given year, care for these patients absorbs over 30 percent of Medicare payments. Several studies have also pointed out that expensive hospital care makes up over half of total spending for dying patients, and that this spending tends to be concentrated just before death. Given these findings, it is clear why an approach to treatment that could reduce Medicare hospitalization payments in the last months of life would have wide appeal.

Hospice in the U.S., with its emphasis on home care, promised one potentially less costly alternative to conventional aggressive therapy. However, early expansion of the hospice industry depended less on financial considerations than on the energy of hospice advocates and increased acceptance from patients and their families. In one decade (1974 to 1984), an

"industry" of over 1,000 hospice programs appeared,<sup>1</sup> and with it a constituency made up of advocates, volunteers, providers and potential patients.<sup>2</sup> National associations have pressured state legislatures to license providers; the National Hospice Organization (NHO) was founded to educate the public, to promote the development of quality of care standards and to work for passage of legislation favorable to hospices. The American Society of Hospice Care and the National Association for Home Care have recently emerged as alternative organizations for hospice providers.

## 2.2        Early Research: The Medicare Hospice Demonstration Program

In response both to public demand for greater choice and to purported cost advantages, public and private health care payers began to recognize hospice care as appropriate and reimbursable in the late 1970's. A Congressional Research Service Report noted in 1982 that 19 Blue Cross associations were sponsoring hospice demonstration projects, and 37 plans had begun to extend coverage to hospice care. Moves to add comprehensive hospice care to state Medicaid coverage had been frustrated by federal regulations; however, a provision of the Consolidated Omnibus Budget Reconciliation Act (COBRA) of

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<sup>1</sup>The Joint Commission on Accreditation of Hospitals (JCAH) used the National Hospice Organization (NHO) Guide to the Nation's Hospices, JCAH's own lists and state hospice association lists to estimate a total of 1,700 hospices "in various stages of development and service delivery" by June, 1986 (JCAH, 1987). Counting hospices is a difficult task. Some organizations identified by the NHO or JCAH are hospices in name only. Some are in a planning stage, and may never be fully operational. An NHO estimate of about 1,200 operational hospices in 1985 probably understates the size of the industry, but the JCAH estimates may err by overestimating the number actually providing hospice services.

<sup>2</sup>Although hospices in the U.S. have been estimated to serve less than 10 percent of the terminally ill Medicare population, many observers argue that up to 25 percent could be served without radically changing the nature of hospice care.

1985 permits state Medicaid programs to pay for hospice services at Medicare benefit levels. New York and Florida have taken steps in this direction.

At the Federal level, the National Hospice Organization coordinated a drive to add a Hospice Benefit to the Medicare program. The first step taken was to try to demonstrate hospice cost effectiveness. In 1980, responding to the NHO and Congressional interest, the Health Care Financing Administration, together with the Robert Wood Johnson and John A. Hartford Foundations, funded a two-year demonstration project designed to compare hospice with conventional modes of care on cost, quality of life, the nature of the clinical intervention and other outcomes. The resulting National Hospice Study (Greer, et al., Final Report of the National Hospice Study. NTIS No. PB86226073/LP. \$48.95) collected information directly from samples of hospice and conventional care patients; in addition, Medicare bills and medical record data for all Medicare beneficiaries in the 26 demonstration hospices were used to study hospice savings.

The NHS was the most comprehensive of several studies of hospice and other approaches to terminal illness begun in the early 1980s; these included an early National Cancer Institute attempt to measure costs in three hospice programs (Kay, 1981), studies of the costs of dying Medicare and Blue Cross patients (Brooks and Smyth-Staruch, 1984; Spector and Mor, 1984), and studies of hospice experiments in several sites in New York state (Hannan and O'Donnell, 1984) and in a Veteran's Administration Hospital (Kane et al., 1984). The Joint Commission on Accreditation of Hospitals launched a major series of surveys in 1980 to gather data needed to formulate standards and criteria for accrediting hospices (JCAH, 1984).

Once the demonstration project was under way, the National Hospice Education Project (NHEP), a political arm of the NHO, turned its attention to

the legislative process. Key members in both Houses of Congress were approached. The NHEP commissioned a separate study of the cost effectiveness of hospice care, with funding from the Warner Lambert Foundation.

### 2.3        Federal Hospice Legislation

Bills to add a Medicare Hospice Benefit were introduced simultaneously in the House and Senate in 1981, based on a draft written by the NHEP, and cosponsored by Representative Leon Panetta and Senator Robert Dole. Although it was too early to draw conclusions on cost effectiveness from the National Hospice Study, the Warner Lambert study (released in 1981 to coincide with Congress' deliberation on the proposed benefit) used a review of past research to argue that hospice care would reduce hospital use and save money over other types of care for the terminally ill. A 1982 Congressional Budget Office analysis, based on interviews with health care professionals, as well as data from the National Cancer Institute, the National Hospice Organization and the Joint Commission on the Accreditation of Hospitals, reached the same conclusion. HCFA's own internal projections were much more conservative; using early HCFA demonstration figures and regular Medicare Part A data, HCFA concluded that hospice might not yield any savings to the Medicare program, and would in fact increase program expenditure by \$455 million over a 5 year period. (HCFA, Office of the Actuary. Memo to the Administrator, April, 1982).

In August 1982, Congress enacted a Medicare hospice benefit (PL 97-248, Section 122 of the Tax Equity and Fiscal Responsibility Act). In spite of the considerable attention paid to hospice savings, cost was not the only consideration that guided Congressional deliberations. Senator Dole introduced the legislation by stressing its role in promoting choice and the quality of life of terminally ill patients and their families (Congressional

Record-Senate. December 15, 1981. S15358). However, it is likely that Congress, by capping inpatient utilization meant to structure the benefit in a manner that would promote savings through substitution of home care for inpatient care. Congress also recognized the risks involved in setting up a reimbursement system for a relatively new and expanding health care industry. Thus, the legislation mandated an evaluation of the cost effectiveness of hospice care under the benefit, and included a sunset provision, effective on November 1, 1986, unless Congress should act to extend the program.

Despite some dissatisfaction with parts of the Hospice Benefit, the National Hospice Organization lobbied vigorously to make the Benefit permanent. On April 7, 1986 Section 9123 of COBRA eliminated the sunset provision. At the same time, each per diem rate was increased by \$10, and hospice was added to the list of services state Medicaid programs could offer with Federal financial participation.

#### 2.4        Private Sector Initiatives

Private payers have added hospice coverage as the federal commitment to hospice increases. Blue Cross and Blue Shield offered a hospice benefit to its federal subscribers in 1985, through a plan that included a \$3,000 per subscriber cap, a five-day inpatient limit and no payment for bereavement care. A survey of 1,115 employers by the Wyatt Company, reported by Moga, (1985), revealed that over 40 percent included hospice care in their group plans. Seven states (Maryland, Colorado, Michigan, Nevada, West Virginia, New York, and Washington) require that insurance plans cover hospice care (Moga, 1985; NHO Hospice News February, 1986). A measure of the "market place"

acceptance of hospice care is seen in recently-announced plans to expand for-profit hospice programs' shares of the market (Paradis and Cummings, in press; Abel, 1986) (state regs).

## 2.5      State Hospice Legislation

States have regulated health care providers through licensure and certification for many years. Medicare's Conditions of Participation for the hospice benefit required that Medicare-certified hospices comply with all state and local licensing laws. By the end of 1985, 33 states had enacted or were in the process of developing enabling legislation to empower a regulatory agency to regulate hospices (or hospice-like services from a non-hospice provider). The following discussion builds on material gathered by Laliberte and Mor (1986) in their review of state hospice regulation for the Medicare Hospice Benefit Program Evaluation.

Regulations in place range from highly detailed rules defining and monitoring hospice (Florida, 1979 and Illinois, 1983, for example) to fairly narrow legislation that may never identify "hospice" as a separate provider. For example, Texas and Connecticut laws originally applied to treatment of terminally ill persons in home care. Later, Connecticut added a definition of "hospice" as an inpatient facility, patterned after Hospice, Inc., the first such program in the U.S., and not the community-based model often identified with American hospice care. Texas set two standards for hospice in 1983: Class A hospices are Medicare certified, and Class B hospices must provide a full range of services, but "core services" are not defined for this group.

Passage of TEFRA was accompanied by an acceleration in the growth of state hospice licensing legislation. Of the 25 laws passed between 1979 and 1986, 15 were passed in 1983-84; since 1984, only one new law has been enacted. Five states cite Medicare Conditions of Participation either as

standards for licensure or to note exceptions. New Mexico, for example, exempts hospices associated with Medicare-certified hospitals, SNFs or ICFs. New York exempts home nursing services from its list of required core services.

Laliberte and Mor note a strong positive relationship between the presence of detailed regulation and the number of hospices (total and Medicare-certified). Hospices with the credentials to become certified have taken a lead in helping to frame licensure laws, to control entry and to promote standards of quality. These laws define hospice as the state hospice industry defines them. As a result, many community-based palliative care programs that fail to meet state licensure standards cannot offer their services as "hospices."

## 2.6      The Medicare Hospice Benefit

The authors of Public Law 97-248 sought to achieve two broad objectives:

- to increase Medicare beneficiaries' access to the hospice alternative;
- to promote Medicare cost containment.

Measures to achieve these goals were either spelled out in the law or left to HCFA to develop as regulations. Major provisions of the law include the following:

Election and certification. Separation and identification of Medicare hospice beneficiaries and providers: hospice patients, certified as terminally ill by a physician, waive their rights to regular Medicare benefits, except for care unrelated to their terminal illness and for care provided by an attending physician, for a lifetime maximum of 210 days (divided into two 90-day and one 30-day benefit periods) and must receive care for the terminal condition in a certified hospice; certified hospices must

meet certain staffing and service provision standards not required of other Medicare providers.

Core services. In particular, Medicare-certified hospices must provide substantially all core services (including skilled nursing, medical social services, physician services and counseling); all services must be available at all times.

Volunteers. Certified hospices must follow standards (to be established through regulation) for using volunteers in providing care.

Interdisciplinary team. Services provided to hospice beneficiaries must follow a written plan of care drafted and administered by an interdisciplinary team which, at a minimum, includes a physician, a registered nurse, a medical social worker, and a pastoral or other counselor.

Other required hospice services, and professional management responsibility. In addition, a certified hospice must provide, directly or under contract, physical, occupational and speech therapy, home health aide and homemaker services, drugs, supplies and equipment and short-term inpatient care for respite, pain control and symptom management. When such care is arranged contractually, the hospice must maintain professional management responsibility for care, wherever the care is provided.

Required services excluded from separate payment. Although the law requires provision of counseling services for certification, specifically bereavement and nutritional/dietary counseling, separate reimbursement for these services is prohibited.

Payment method. The law prohibits explicit reimbursement for counseling and provides for cost sharing in outpatient drugs and inpatient

respite care. However, the law was ambiguous on overall payment specifying only that "reasonable" costs should be paid.

Reimbursement cap and inpatient limit. Cost savings were to be encouraged by limiting the total inpatient days for which a hospice can receive full reimbursement to 20 percent of total annual patient days of enrollment; in addition, a reimbursement ceiling was to be set by multiplying a hospice's annual Medicare patient census times a fixed percent of the estimated Medicare cost per cancer patient in a conventional care setting over the last 6 months of life.

Physician payment. Medicare payments to attending physicians not employed by the hospice were to be covered under Supplementary Medical Insurance (Part B); care provided by a hospice physician was to be paid as part of the hospice benefit.

Payment methodology. The final choice of a payment method reflects contemporary Medicare policy. Although some assumed that the "reasonable cost" language in the law meant that Congress intended hospice care to be reimbursed retrospectively on a cost basis, the Administration developed a prospective per diem payment system. Every beneficiary day in a certified hospice is paid at a fixed rate, depending on the setting in which care was provided and the resource intensity of care. Inpatient days are classified as either respite days (periods of at most five consecutive days of low intensity care provided to give family and other informal caregivers some relief) or general inpatient days, provided to manage patients' symptoms or control pain. Home days are defined to be either continuous care days (characterized by high intensity, continuous nursing care on a crisis basis), or routine days (all other days spent at home, whether or not care is provided).

Initially, HCFA used data from its demonstration project to set three of the four per diem rates. Routine and continuous home care rates are based on estimates of nursing and therapy utilization by patients at home, plus costs of drugs (adjusted for allowed copayments), supplies, equipment and coordination by the interdisciplinary team. As Table 2 shows, the continuous care rate is defined in hourly terms, and is payable for a minimum of 8 hours a day. The general inpatient care rate, based on costs of the 11 hospital-based hospices in the demonstration, covers both routine and ancillary services. Respite care is at the national average Medicare cost per day for skilled nursing facility care, adjusted downward for allowed copayments; demonstration data were not used to set this rate because experience with respite care under the demonstration was limited to less than one percent of the patients. Each rate is further adjusted by HCFA's wage index, which reflects geographic variation in labor costs.

Physician services are the lone exception to this prospective payment methodology. Excluding the physician component of hospice administrative expense (which is paid through the interdisciplinary team component of the per diem rates), hospice physician services delivered directly to patients are paid at 100 percent of reasonable charges. Care provided by an attending physician who is not employed by the hospice is paid through Medicare Part B, at 80 percent of reasonable charges.

Setting a value for the reimbursement cap provoked some controversy. Although the law defines the cap in terms of the national average Medicare per capita expenditure for cancer patients in the last six months of life, measuring it is a difficult task. Working with an estimate of \$19,000 of conventional care costs in the last 6 months, Congressional Budget Office staff estimated the hospice payment cap to be \$14,600 (75 percent of

Table 2

Medicare Hospice Benefit Payment Rates<sup>1</sup>

| <u>Category</u>        | <u>Rate</u>  | <u>Services Covered</u>   |
|------------------------|--|---|
| General inpatient care | \$281 per diem   | Inpatient routine care; ancillary services (oxygen, laboratory, pharmacy, etc.)   |
| Inpatient respite care | \$65.33  | Inpatient (skilled nursing care) routine care; drugs, supplies, equipment, interdisciplinary group  |
| Routine home care      | \$63.17 per diem (\$46.25 from November, 1983 through September 30, 1984, \$53.17 from October 1, 1984 through March 31, 1986) | Nursing, home health, social service/therapy,<br>Home respite,<br>Interdisciplinary group,<br>Drugs, supplies, equipment,<br>Out patient hospital therapy |
| Continuous home care   | \$15.36 per hour<br>(\$368.67 per day)   | Nursing, therapy,<br>Drugs, supplies, equipment,<br>Interdisciplinary group   |

<sup>1</sup>Rates in effect from April 1, 1986.

\$19,000) (CBO, June, 1982). The House Ways and Means Committee, finding this estimate to be excessive, inserted a lower proportion into the bill (40 percent), and computed a cap amount of \$7,600 (40 percent of \$19,000). HCFA's first estimate of \$4,232 per patient, published as part of the proposed regulations in August 1983, was well below the amount Congress expected; HCFA applied the 40 percent factor to a base amount of \$10,580, rather than \$19,000. Even though CBO subsequently admitted that their methodology was faulty, (CBO, June, 1985) Congress and hospice advocates found HCFA's estimate unacceptably low, and legislation (PL 98-90) was subsequently enacted to set the cap for FY1984 at \$6,500 per patient, to be adjusted annually for changes in the medical care component of the consumer price index.

Definitions and standards. Regulations included definitions and standards. While Congress specified a list of core services that all certified hospices must provide, the scope of hospices' professional management responsibilities in contractual arrangements for other covered services was left to regulatory development and operating experience. HCFA devised standards to assure the continuity of a patient's plan of care, particularly when a hospice contracts for hospital or other inpatient services. At the same time, many of the legal and administrative implications of professional management responsibility were left to be established through precedent. Issues such as legal liability (is the hospice or the subcontracting hospital liable for malpractice claims regarding hospice-related care furnished in the hospital?) were not addressed. The extent of a hospice's direct involvement in managing subcontractors' performance was left to be resolved on a case-by-case basis through contract negotiations.

## 3.0 STRUCTURE AND PROCESS IN THE U.S. HOSPICE INDUSTRY

### 3.1 Goals and objectives of hospices

Hospices provide medical and psychosocial therapies for terminally ill patients and their families in a home-like environment, to control physical pain and disease symptoms and to prepare the family for the patient's death and support it in its grief. In 1979, the National Hospice Organization developed a list of "desirable" characteristics of hospices.

- unit of care: the terminally-ill patient's family is the unit that receives hospice services. What constitutes a family depends upon who, beside formal caregivers, are considered essential to the patient's care.
- supervision of care: hospices should use an interdisciplinary team, including physicians, nurses, medical social workers, and counselors, to plan and manage the provision of services.
- continuity and integration of care: care should be available 7 days a week, 24 hours a day, and should be closely integrated (particularly between home and inpatient settings) by the interdisciplinary team.
- preventive clinical interventions: drugs and other therapies should be used to prevent pain rather than merely alleviate it.
- education: hospice responsibility toward patients, families and staff includes education on matters related to death and dying.
- bereavement: hospice responsibility to support and comfort the family extends beyond the patient's death.
- volunteerism: volunteers make significant contributions both to administering the program and to providing family support services.

Two characteristics often linked to hospice are conspicuously absent from this list: orientation toward cancer patients, and emphasis on home care.

**Orientation toward cancer patients:**

Because over 90 percent of hospice patients suffer from cancer (JCAH, 1987), it is often assumed that hospice is a cancer program. However, the prevalence of hospice cancer patients reflects the fact that the progress of some cancers into a terminal phase is more predictable than that of other conditions. Thus physicians have been more willing to offer a terminal prognosis for advanced cancer patients than for other patients with chronic, life-threatening conditions such as diabetes and hypertension.

**Emphasis on home care:**

Pioneers of hospice in Great Britain hoped to provide inpatient care in a home-like atmosphere. American hospice advocates have often translated home-like into home care; dying at home, and receiving all but the most technically demanding services at home are considered desirable for both patients and families. However, there is disagreement on this matter within the U.S. hospice movement. Corless notes that "(implicit) in the (Medicare Hospice Benefit) Regulations is a model of hospice as home care." She fears this means that "(the) interest in exploring a variety of organizational models is being stifled.."; home care should be"...a viable alternative, not the only option." (Corless, 1985; pages 284, 285).

Information reported in this section comes principally from three sources: the National Hospice Study (Greer, et al., 1986), results from a series of surveys conducted by the Joint Commission on Accreditation of Hospitals between 1981 and 1984 (JCAH, 1985), and findings from a JCAH Survey of 145 Medicare certified and 191 noncertified hospices, conducted in 1986 and funded by the Health Care Financing Administration as part of the Hospice Benefit Evaluation. The last source provides the most current and complete picture of U.S. hospice structure and process that is available. Table 3

Table 3

Comparisons of Hospice Patient Characteristics:  
The Medicare Hospice Benefit (FY85) and The National Hospice Study

| Characteristic    | Medicare Hospice Benefit |                                 | NHS                   |                                |
|-------------------|--------------------------|---------------------------------|-----------------------|--------------------------------|
|                   | Hospice<br>(N = 5991)    | Conventional Care<br>(N = 7467) | Hospice<br>(N = 5295) | Conventional Care<br>(N = 588) |
| <b>Age</b>        |                          |                                 |                       |                                |
| Less than 75      | 54%                      | 47%                             | 71%                   | 62%                            |
| 75 or over        | 46                       | 53                              | 29                    | 38                             |
| <b>Sex</b>        |                          |                                 |                       |                                |
| Female            | 53%                      | 54%                             | 53%                   | 51%                            |
| Male              | 47                       | 46                              | 47                    | 49                             |
| <b>Race</b>       |                          |                                 |                       |                                |
| White             | 91%                      | 87%                             | 93%                   | 83%                            |
| Other             | 9                        | 13                              | 7                     | 17                             |
| <b>Diagnosis:</b> |                          |                                 |                       |                                |
| Colon             | 29%                      | 20%                             | 15%                   | 14%                            |
| Lung              | 26                       | 21                              | 24                    | 23                             |
| Breast            | 6                        | 4                               | 10                    | 9                              |
| Prostate          | 11                       | 9                               | 8                     | 8                              |
| Other cancer      | 29                       | 46                              | 44                    | 46                             |
| Length of Stay    | 32.1 days                |                                 | 69.1 days             |                                |

Sources: FY85 HCFA Hospice Benefit Enrollment File; Greer, et al. Final Report of the National Hospice Study. 1986.

compares characteristics of Medicare Hospice Benefit patients with NHS patients. In Table 4, major findings from the 1986 JCAH survey regarding differences between Medicare certified and noncertified hospices are summarized.

### 3.2        The Hospice Patient

Most hospices serve elderly patients. The average Medicare Benefit patient is 74 years of age. The average age reported in the literature ranges from 60 to 75 years. Pediatric hospice care, a relatively new phenomenon, provides the only current exception to this rule (Lauer and Carmitta, 1980); in many instances, children and adults have been served by the same program. Young male AIDS victims have needs that may have to be met through separate hospice units; given the fear surrounding this condition, it is unlikely that hospices oriented toward elderly populations will be inclined to admit AIDS patients. (See below)

Hospice patients are generally cancer victims. The most common major sites are lung, colorectal, prostate and breast cancers. Data from the Benefit Evaluation and other large scale studies such as the NHS have estimated that as many as 5 to 10 percent suffer from a chronic condition other than cancer (hypertension, end-stage renal disease, diabetes).

There are several factors that might affect decisions of a terminally-ill patient and his/her caregiver regarding hospice enrollment.

- Financial barriers. The Hospice Benefit has reduced or eliminated the burden of paying for direct medical expenses for most Medicare beneficiaries. Added coverage for hospice care in state Medicaid programs, Blue Cross and commercial group health policies has increased access to hospice care of the non-Medicare populations. For patients with no coverage, many hospice programs have generated philanthropic revenues from foundations and individuals, and have adjusted charges to meet patients ability to pay.

Table 4

Comparisons of Medicare-Certified and Noncertified Hospices: Structure and Process

| Category  | Medicare-Certified        | Noncertified                    |
|---|---------------------------|---------------------------------|
| <u>Organizational Affiliation</u>                                   |                           |                                 |
| Hospital-based  | 27%                       | 50%                             |
| HHA-based   | 40%                       | 16%                             |
| Freestanding  | 33%                       | 34%                             |
| <u>Size</u>   | 14.7<br>patients/month    | 9.9<br>patients/month           |
| <u>Provision of home and inpatient services</u>                     | Virtually all             | Home: 92%<br>Inpatient: 61%     |
| <u>Physicians</u>   |                           |                                 |
| Medical directors paid vs. volunteer                                | Most paid part-time (64%) | Most volunteers part-time (74%) |
| Proportion approve care plan:                                       |                           |                                 |
| medical director  | 83%                       | 67%                             |
| attending physician   | 66%                       | 44%                             |
| <u>Nurses</u>   |                           |                                 |
| Proportion providing  |                           |                                 |
| continuous nursing care   | 97%                       | 46%                             |
| intermittent nursing care   | 99%                       | 96%                             |
| Proportion with specified minimum requirements for nurse supervisor | 92%                       | 81%                             |
| Responsibilities of patient care coordinator in home setting:       |                           |                                 |
| chair interdisciplinary team (IDT)                                  | 89%                       | 81%                             |
| ensure plan of care carried out                                     | 93%                       | 67%                             |
| ensure documentation of IDT services                                | 94%                       | 65%                             |
| obtain/transmit transfer summaries                                  | 87%                       | 62%                             |
| Caseload (% with 5 or fewer hospice patients)                       | 48%                       | 66%                             |
| 24-hour nursing services  | 95%                       | 82%                             |
| Clinical supervision of contract care:                              |                           |                                 |
| at home   | 91%                       | 53%                             |
| inpatient setting   | 57%                       | 27%                             |
| <u>Bereavement</u>  |                           |                                 |
| Provision of services   | 100%                      | 98%                             |
| Frequency (contacts per family):                                    |                           |                                 |
| volunteers  | 3.86                      | 4.04                            |
| social workers  | 3.57                      | 3.15                            |
| Proportion with over 50 families receiving service                  | 48%                       | 27%                             |

Table 4

Comparisons of Medicare-Certified and Noncertified Hospices: Structure and Process  
(continued)

| Category   | Medicare-Certified | Noncertified |
|--|--------------------|--------------|
| <u>Dietary/Nutritional Counseling</u>  |                    |              |
| Provision of services:   |                    |              |
| home   | 100%               | 86%          |
| inpatient  | 91%                | 84%          |
| Use of registered dieticians:  |                    |              |
| home   | 82%                | 58%          |
| inpatient  | 72%                | 51%          |
| <u>Admissions</u>  |                    |              |
| Percent with cancer primary diagnosis  | 90%                | 93%          |
| Criteria for admission:  |                    |              |
| cancer only  | 3%                 | 4%           |
| require primary care person  | 83%                | 78%          |
| no prognosis criteria  | 27%                | 11%          |
| Presence of informed consent process   | 70%                | 36%          |
| Provide transfer summaries   | 41%                | 23%          |
| Maintain written contract agreements defining scope of work                    | 62%                | 24%          |
| Receive clinical record/care summary from contractors or cooperating providers | 90%                | 40%          |
| Volunteers:  |                    |              |
| use volunteers   | 100%               | 97%          |
| no minimum education required for volunteers                                   | 92%                | 75%          |
| Volunteer-intensive<br>(80% or more services provided by volunteers)           | 4%                 | 33%          |
| Average number of volunteers:  |                    |              |
| home   | 4.33               | 3.20         |
| inpatient  | 26.42              | 17.32        |

Source: JCAH, "The Nature, Process and Modes of Hospice Care Delivery." Final Report (Draft) 1987.

- Availability. In 1984, 2,296 (out of 3,053) counties offered no formal hospice services (using NHO membership and operational status as criteria). Hospice growth has been most rapid in East and West Coast urbanized areas.
- Preferences of families/caregivers. Psychological barriers to choosing hospice care, in the general population and among physicians, may have declined as the availability of hospice has grown.
- Lack of information. Increased availability should stimulate wider awareness of hospice care. Of course, the rapid changes in the health care delivery system over the past decade may have clouded consumers' perceptions of what options are available (Aday, Fleming and Anderson, 1984; Erman and Gabel, 1985).

Respondents to the 1984 Aging Supplement to the Health Interview

Survey (HIS) were asked if they were familiar with the concept of hospice and if so, whether or not hospice was available to them. Mor and Hendershot (1986) evaluated these data and found several interesting patterns:

- The older respondents were less familiar with the hospice concept. Of those 55-64 years of age, 40 percent were familiar with hospice; this figure decreases to 15 percent for respondents over age 85.
- Familiarity was associated with availability. Only 7 percent of respondents for whom hospice services were not available knew what hospice care was; 28 percent of those with access to a hospice program were familiar with the concept.
- Women were more likely than men to be familiar with hospice (38 percent, compared to 31 percent).
- City residents (38 percent) were somewhat more likely to be familiar with hospice than rural residents (31 percent), except in the Northeast, where rural respondents were more knowledgeable than urban respondents. However, proportionately more rural respondents who knew about hospices had no access to one (45 percent, compared to 19 percent of city respondents).
- Past experience with cancer had only a small effect on familiarity with hospice; 40 percent of persons with a prior cancer experience were familiar with hospice, compared to 35 percent without such an experience.

Evidence that most Americans are unfamiliar with hospice care is not surprising. Most individuals' knowledge of health care alternatives comes from experience. Bonham et al. (1986) found that providers introduced the idea of hospice to patients in almost all of the cases that they studied.

Hospice enrollment averages one to two months. Enrollees in Medicare-certified hospices averaged 32.1 days in FY85. Some studies report higher figures. NHS patients averaged 69.1 days. Patients in a VA experiment stayed 97 days on average (Kane et al., 1984). The median enrollment, which is at the midpoint in the distribution of enrollments, is usually lower than the average (which is pulled up by some patients with very long enrollments). Median enrollments have generally been 25 to 30 days, although Perkins and Jonsen (1985) report a 12-day median for hospice patients treated in an inpatient unit.

Hospice patients have also tended to be white; 9 percent of Benefit patients who died in FY85 were nonwhite. In the NHS, 7 percent of patients were nonwhite. Kane's unique patient group (male veterans), included 41 percent nonwhite, but this is clearly an exception. No conclusive pattern emerges on the balance between men and women, although most studies show slightly more women enrolled than men: 53 percent in the NHS, 62 percent in Meyers et al. (1983), 50 percent or more (Oliver, 1985; Barries, et al., 1985; Bonham, et al., 1986). Thus far, the Medicare Hospice Benefit has enrolled a larger percentage of women (53 percent in FY85).

### 3.3        Structure of the Hospice Industry

Hospice care in the United States is offered by a wide variety of institutions; it may be provided by a loosely structured community-based coalition of volunteer groups or through a department in a major teaching hospital. Following terminology adopted by the JCAH, hospices are usually

classified as hospital-based, community-based (home health agency-based) or independent (freestanding). Over half of U.S. hospices are provider-based; according to JCAH, of these, roughly 867 (51 percent) are hospital or nursing home-based hospices, and 272 (16 percent) are home health agency-based hospices (JCAH, 1985). The balance of 1139 freestanding hospices includes both community-based coalitions and institutions with their own beds. The three-way breakdown among hospital-based, HHA-based and freestanding hospices has sometimes been replaced for research purposes, particularly in the National Hospice Study (NHS), by a two way distinction between "bedded" hospices (those that provide inpatient care directly, usually hospital-based or freestanding units) and others (those that arrange for other providers to furnish inpatient care informally or by contract.)

The typical hospice program is a relatively small, labor intensive operation. Medicare-certified hospices participating in the JCAH 1986 survey averaged 14.7 patients per month, compared to 9.9 patients in noncertified hospices (JCAH, 1987). According to earlier research, the average number of patients served per month ranges from about 10 (in "bedded" programs) to 20 (in other programs) (Mor, unpublished NHS data; Russell, 1984). JCAH reported that the ratio of paid home care staff to patients was about 0.62; however, when the average number of volunteers in each program are included, the ratio of staff to patient tripled (JCAH, 1985). Size and affiliation seem to be related to leadership and organizational style. Paradis et al. (1983) found that larger programs and hospices affiliated with providers tended to be more integrated with the traditional health system, depending less on volunteers and involving physicians more in leadership roles.

Even though provider-based hospices may have been prone to adopt traditional medical models of organization, their admissions standards have

not necessarily been more stringent than those of freestanding hospices. Research indicates that the majority of hospices require a terminal prognosis of 6 to 12 months; few hospices have no prognosis requirement (7 percent of HHA-based, and twice this percentage for hospital-based and freestanding hospices, according to JCAH, 1987). Provider-based hospices are less likely than freestanding hospices to restrict admission to cancer patients. Five percent of freestanding hospices in the JCAH 1986 Survey admitted only cancer patients compared to none (HHA-based) and 5 percent (hospital-based). Twenty-four percent of free-standing hospices in the National Hospice Study served only cancer patients, compared to 18 percent of hospital-based and 12 percent of HHA-based programs.

Most hospices (79 percent of the 1986 JCAH sample) require as a condition of admission that a primary care person (PCP) be available. O'Connor and Kaplan (1986) found that 68 percent of 451 hospices they surveyed had this requirement. Medicare-certified hospices in the JCAH Survey were somewhat more likely (83 percent) than noncertified hospices (78 percent) to require a PCP. These data cannot prove that certification requirements caused hospices to impose the PCP requirement. It is quite likely that many implemented this rule well before applying for certification. Kieffer and Wakefield (1986) report that hospices have developed ways to provide substitute PCPs, using paid care providers and church volunteers. These tend to be large programs with a full array of services and substantial Medicare funding.

Coordinated, direct provision of both inpatient and home care is more prevalent among provider-based than freestanding hospices. According to the JCAH (1985), only 35 percent of freestanding programs directly provided both home and inpatient care (compared to 76 percent of hospital-based and 40

percent of HHA-based hospices) Connor's (1986) study of National Hospice Organization members reported that only 64 percent of responding hospital-based hospices offered both home and inpatient care. In addition, JCAH showed that freestanding hospices were almost as likely to contract for home care services as hospital-based hospices (62 percent and 73 percent respectively). However, formal contracting for inpatient care has been relatively infrequent among freestanding hospice programs (19 percent) and hospital-based programs (8 percent). Since over half of these programs provided only home care on a direct basis, informal, ad hoc arrangements for hospitalization were the rule in many hospices (JCAH, 1985).

### 3.4        The Hospice Intervention

At a clinical level, hospice offers palliative therapy, to control patients' pain and symptoms, and counseling to help patients and families cope with anxiety, depression and grief both before and after death. Clinicians engaged in hospice and nonhospice palliative care have written protocols to guide practitioners in pain and symptom control that stress heavy use of analgesic drugs, supplemented by radiotherapy, nerve blocks, physical therapy and, in some instances, relaxation therapy and massage. The majority of hospice patients, regardless of the setting for treatment, receive prescriptions for drugs to control pain; however, massive preventive doses of medication have not been widely used in U.S. hospices.

Most protocols have originated from research and practical experience in hospital-based settings, where regular medication can be effectively coordinated with the efforts of skilled therapists. Clark (1984) provides a useful review of the properties of analgesics. Dosage and scheduling are critical to effective pain control. Baines (1984) notes that regular heavy doses of analgesics administered to prevent pain are principles applied at St.

Christopher's Hospice in England. This process includes careful monitoring and continual reassessment, to balance dosages and compensate for drugs' side effects. Research suggests that compliance with such protocols may be more difficult in home care settings (Galt and Galt, 1984). When primary care persons have ongoing responsibilities for administering drugs, a careful, thorough training program is important to successful pain control.

Drugs may also be used to control symptoms frequently encountered in terminal illness, such as nausea, constipation, shortness of breath and depression; however, less than half of hospice patients reporting these symptoms also received prescriptions for drugs to control them. For example, in one study 32 percent of patients who reported nausea had a prescription for an anti-emetic drug. (Reuben and Mor, unpublished, 1985). Provision of oxygen and respiratory therapy, two accepted methods for dealing with chronic shortness of breath, were utilized in less than half of the cases surveyed in the NHS (NHS, unpublished). The use of antidepressants during therapy in hospice has been limited; limited understanding of the origins of depressive moods and failure to develop written protocols have apparently led hospices to depend almost entirely on counseling to relieve restlessness and anxiety (Goldberg and Mor, in press).

Avoidance of invasive procedures and "excessive" diagnostic testing is as important to the definition of hospice care as is palliative drug therapy. Although radiotherapy and chemotherapy can be used both to reverse a cancer and to relieve pain (Richter and Coia, 1986), evidence suggests that these methods have rarely been used in hospice care for any purpose, although they appear to be widely used in conventional care for palliation. In the HCFA demonstration, as reported by the NHS, under 10 percent of hospice patients received either procedure in the last weeks of life. (Greer, et al.,

1986). Surgery was even less common (less than 2 percent). Bains, et al., (1985) note that drugs can often be used successfully for patients for whom surgery is contraindicated. Diagnostic x-rays are rarely used for hospice patients (20 percent of HHA-based and 14 percent of hospital based patients, according to findings from the NHS); in contrast, over 60 percent of patients treated by conventional means (usually in hospitals) were x-rayed in the last weeks of life (Greer, et al., 1986). Smith and Veglia (1986) showed that 53 hospice patients received significantly fewer procedures, diagnostic tests and special therapies than a control group of 50 non-hospice patients. Perkins and Jonsen (1985) reported an average of 19.5 lab tests over a 10-day period for hospitalized terminally-ill patients, compared to 3.6 and 1.0 in two hospice settings. Oxygen use did not differ between hospice and non-hospice settings in Smith and Veglia's study.

Bereavement counseling, a service widely identified with hospice's family-oriented approach, is provided in most hospices (over 90 percent in the 1985 JCAH survey). Formal counseling is only one of several techniques hospices use to support families in their grief, techniques that include sponsorship of support groups and social functions. It is generally agreed that hospice involvement with the family after a patient dies must be tailored to individual circumstances. Some families neither want nor need counseling. Recent research suggests that nearly one-third of all hospice patients' families never receive bereavement counseling services; it is not clear how many of these wish they had received counseling (NHS, unpublished). Kane (1986) reports that fewer than one quarter of all bereaved families requested bereavement services beyond an initial followup.

NHS data show that, although almost all hospices use volunteers in bereavement work, visits to families are conducted principally by nurses.

This is particularly true among hospital-based hospices, which are also least likely to use volunteers in bereavement programs. HHA-based and freestanding hospices depend more on volunteers (100 percent of freestanding hospices in the NHS used volunteers for this service) and less on nurse involvement (NHS, unpublished). Hospice volunteers generally provide psychosocial, as opposed to physical, care (Hughes, 1986; Dowe-Warnboldt and Ellerton, 1985-86). These recent studies confirm the continued importance of volunteers in hospice.

Dietary and nutritional counseling, a service singled out for special attention in this evaluation, has not been widely used in hospices even though research in terminal illness has stressed the importance of nutrition as it affects patients' quality of life. JCAH (1987) reports that most surveyed hospices (over 80 percent) offered this service. However, other research shows that actual utilization of services is relatively infrequent. Only 4 of the 26 HCFA demonstration hospices submitted claims for this service. Intensive analgesic drug therapy can produce uncomfortable side effects such as nausea and vomiting, which can be countered either by anti-emetic drugs or by diet change. Weight loss and other physical changes in the last weeks of life may be accompanied by loss of appetite. Because families express feelings of love and nurturing in part by feeding, this change in a patient's status can be troubling for home caregivers. Thus, counseling on nutritional matters in hospice can address not only the linkage between diet, methods of feeding and a patient's changing physical condition, but also families' feelings of guilt and anxiety over the patients' reaction to food and feeding (Dixon, *et al.*, 1985).

### 3.5        Process: The Issue of Clinical Control

To be certified for Medicare reimbursement, a hospice must have clinical control over services provided in hospice and nonhospice settings in

order to maintain continuity of care throughout the patient's enrollment. One way to achieve this end is to require hospices to provide directly all services needed to treat terminal conditions. The core services requirement stipulates that most home care services should be furnished by hospice staff, but permits contracting for inpatient care. As we have seen, a significant fraction of U.S. hospices has provided home care services on contract. Also, of those hospices that provide no direct inpatient service, many have not formally contracted with hospitals or skilled nursing facilities to provide this care. For some hospices, then, core service requirements represent a major change in practice.

Hospices' control over directly-provided care services will be effective only if staff are adequately trained. JCAH data indicate that barely a majority of the hospices surveyed felt they were in compliance with standards regarding training in physical symptom management (JCAH, 1985).

Effective control also requires that hospice team managers both communicate hospice goals to nonhospice providers of service and, in turn, remain fully informed about what services have been provided in all settings. In addition to formal written contracts, effective case management requires a plan of care for each patient, shared among hospice and non-hospice providers, and a complete system of medical records. According to the 1986 JCAH survey, less than half of the hospices that responded exchanged care plans across settings (41 percent of certified and 23 percent of noncertified hospices).

### 3.6 Hospice and the AIDS Epidemic

The future of hospice care in the United States will be shaped by many social, demographic and financial challenges. Acquired immune deficiency syndrome (AIDS), presents one such challenge. If hospices follow through on the National Hospice Organization's call to serve the needs of terminally-ill

AIDS patients, they will face a costly, unpopular struggle against overwhelming social and epidemiologic forces. Some would argue that the ideals behind hospice leave no room for doubt: the needs of all terminally-ill patients should be met. But individual hospices will probably make "pragmatic" decisions, based on available resources and the attitudes of staff and the community.

The dimensions of the AIDS epidemic have been documented; in the U.S. nearly 20,000 people now have AIDS, 100 to 200 thousand have "AIDS-related complex" (of whom 10 to 20 percent will progress to AIDS) and one to two million are infected. No patient with an unequivocal diagnosis of AIDS has survived the disease.

AIDS patients present with a host of physical and psychosocial problems. Rare neoplasms (e.g. Kaposi's sarcoma) and "opportunistic infections" (diseases that are normally harmless against a healthy immune system) are accompanied by loss of appetite, incontinence, increasing immobility, cognitive and personality changes, and tendency toward depression and psychoses. Multiplicity of symptoms is a well-documented characteristic of terminal illness. Among AIDS patients, the severity of these symptoms often requires either hospitalization for long periods or constant nursing care well before the crisis period that occurs during the last month of a normal cancer illness.

In addition, AIDS patients may carry a burden of guilt and a sense of isolation from society and often from family and friends. Public attitudes toward "unacceptable" lifestyles are only partly to blame. Hemophiliacs and, increasingly, sexually active heterosexuals share with homosexuals and intravenous drug users a stigma surrounding this condition that is shaped by ignorance of how AIDS is transmitted. Hospices that choose to serve AIDS

patients will have to work to change this environment of fear through education, in order to maintain community and family-centered approaches to care.

Only a small proportion of active AIDS patients have begun to receive experimental drugs designed to arrest the process. After early attempts to combat AIDS-induced diseases with aggressive medical interventions, most health care providers have moved toward a palliative approach: regular nursing care, drugs, palliative radiation and other therapies where indicated. This shift away from attempts to cure makes hospice a logical intervention. However, Riven (1984) found that 35 percent of AIDS patients surveyed spent over half of their post-diagnosis time in a hospital.

At this time, AIDS is an "urban" disease, and major differences have emerged among cities in hospitalization rates. San Francisco, with a long tradition of hospice care, a sympathetic city government and a reasonably well-developed network of volunteers and agencies in the gay community has provided community-based alternatives to hospitalization (Robinson, 1984, Callian, 1984). New York, in contrast, has not generated the community support needed for these kinds of networks. Also, many of the New York AIDS patients are poor and/or homeless. Consequently, hospitalization rates for AIDS patients have been twice as high in New York as in San Francisco.

Evidence on how much AIDS costs is fragmented: most studies put the figure at over \$40 thousand per case (Quinn, 1985, Landsman et al., 1985) but treatment modalities have changed so rapidly that these estimates may not be representative. Hardy et al., (1986) estimated that the first 10,000 AIDS cases cost, in direct and indirect costs, over \$1.4 billion. Although reduced

hospitalization should be a source of savings, AIDS patients will still require expensive, regular nursing care over a long period of time.

From the patients' perspective, AIDS is a financial as well as a physical disaster. For a large proportion of the affected population (young working men), group health coverage is available at diagnosis and for as long as the patient remains employed. Loss of coverage forces the patient to "spend down" to poverty in order to receive either Medicaid assistance or Social Security Supplemental Security Income. Because there is a two-year waiting period, most AIDS patients die before they qualify for Disability coverage under the Medicare program. In the future, individuals at risk may even be unable to buy commercial health insurance, if companies are successful in convincing state insurance commissions that blood test and/or "lifestyle" screens provide valid grounds for denying coverage. The patients' financial dilemma becomes the health provider's dilemma. If third party payers refuse to cover most AIDS-related expense, the costs of treatment will be shifted to the patient, hospital and/or hospice.

Hospices are likely to be particularly vulnerable, because they are, by philosophy, less prone than other providers to "offload" indigent patients to government-owned hospitals or nursing homes. Therefore hospices that accept AIDS patients may be forced to seek new revenue sources. Medicaid may offer a partial solution, in states that have added hospice to their list of approved services. However, if projections of AIDS incidence are correct and if a "cure" for the condition is not made widely available in the next five to ten years, then demands on the health care system, focused more and more on providers of palliative services, will grow. Hospices and other providers that accept AIDS patients face difficult choices that could determine their institutional survival.

3.7

Will the incentives inherent in the Medicare Hospice Benefit influence the growth and composition of the hospice industry?

This brief review of U.S. hospices and how they function shows great diversity in structure and process. Some applaud this situation, in the belief that diversity fosters innovation and promotes choice. Others look for ways to standardize hospice practice, taking the position that some degree of uniformity is necessary to maintain high quality of care.

Does the Medicare Hospice Benefit contain incentives that tend both to encourage home care and to favor hospices that operate like traditional health care providers? Critics charge that the Benefit will attract only a select group of existing hospices, an outcome that could reduce access to hospice care for some Medicare patients. In addition, the experimentation that has characterized the hospice movement in the past may be curtailed if new entrants into the industry try to conform to a standard "acceptable" organizational model. There is considerable agreement that the Benefit has affected the organizational features of hospice care, moving it further into the medical mainstream (Tehan, 1985; Abel, 1986; Paradis and Cummings, in press).

Evidence from the JCAH surveys presented in this section depicts a "typical" Medicare certified hospice that, compared to a typical noncertified hospice, serves a larger caseload, uses proportionately more paid, full-time, highly-qualified staff, adheres more thoroughly to processes of clinical planning, patient assessment and follow-up on plans of care, documents its own activities more fully and requires more documentation and compliance with hospice standards from contractors and cooperating providers.

There are also specific ways in which the Benefit is expected to work to the advantage of provider-based programs. Provider-based hospices may find conformance with the core services and professional management

responsibility requirements less burdensome than freestanding hospices. As noted earlier, provider affiliation has been shown to be associated with a relatively traditional approach to delivery of care, relying on formal contracting and written care plans. The core services requirement that nursing and counseling services be directly provided seems tailored for home-care oriented hospices.

There are ethical and legal issues associated with the professional management responsibility requirement that work to the advantage of hospital-based hospices. Several hospices contacted prior to implementation of the Benefit pointed out that forcing hospitals to share management of care with hospice interdisciplinary teams would make contracting for inpatient care difficult (Kusserow, 1984). The issue here is not only alleged differences in philosophy between team members and hospital staff. Most hospital administrators would assume that their licensure status depends on maintaining control over the quality of care provided within their facilities. However, the question of legal liability for care ordered by a hospice team and provided under contract in a hospital has not been settled.

Other provisions, such as the limit on inpatient days and a cap on total Medicare payments favor hospices that can deliver care at home efficiently regardless of provider affiliation. By making adherence to the inpatient cap both a requirement for continued certification and a reimbursement limitation<sup>1</sup>, Congress clearly favored a home-oriented model of hospice. The cap on total payments encourages hospices to seek patients with relatively well-defined prognoses and limited needs for expensive care. Medicare-

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<sup>1</sup> Inpatient days provided under the 20 percent cap are currently reimbursed at the general inpatient care rate of \$281 per day. Additional inpatient days are reimbursed at the routine home care rate.

certified hospices in the JCAH 1986 survey were more likely than noncertified providers to establish prognosis criteria for admission. Finally, some patients may need expensive hospitalizations because they lack adequate home supports. Many hospices now require a potential enrollee to have a primary care person (PCP); financial incentives in the Benefit could accelerate this practice among Medicare-certified hospices, although the percentage now requiring a PCP is already nearly 80 percent in both certified and noncertified hospices.

IMPLEMENTATION AND OPERATION UNDER THE MEDICARE HOSPICE BENEFIT

During the first year of the Benefit, hospices faced considerable uncertainty about the implications of participation. Some probably chose to wait until Congress decided whether or not to eliminate the sunset clause. Final regulations were not published until December 16, 1983, over a month after the program's starting date (November 1, 1983). After considerable discussion, the routine home care rate, first set at \$53, was lowered to \$46 in the final rules; then, in October 1984 the rate was raised back to \$53. Finally, Congress on April 8, 1986 legislated a flat \$10 increase in all Hospice Benefit per diem rates, effective on April 1, 1986. Concern over the reimbursement cap and core services requirements also led to new legislation. Congress overrode the cap setting methodology in the original law to set a per patient cap of \$6500. Finally, later, in response to concerns about the effects of core services requirements on small rural hospices, Congress established a method by which a hospice could apply for a temporary waiver of the requirement that nursing services be provided directly.

4.1       How many and what kinds of hospices were certified?

Medicare-certified hospices are overwhelmingly provider-based (affiliated with a hospital, home health agency or skilled nursing facility), as Table 5 shows; of these, there are two HHA-based hospices for each hospital-based hospice. Freestanding programs are somewhat underrepresented; an estimated 33 percent of U.S. noncertified hospices were unaffiliated in 1985 (JCAH, 1987) while they comprised only 27 percent of certified hospices in FY84 and FY85. In contrast, HHA-based hospices participated at a rate higher than their proportion in the hospice population. The JCAH estimates that in 1985 51 percent of noncertified hospices were hospital-based and 16

**Table 5**  
**FY 84, 85 Medicare-Certified Hospices, By Affiliation**

| Affiliation    | Certified as of: |          |          |          |
|----------------|------------------|----------|----------|----------|
|                | 11/13/84         | 10/1/85  |          |          |
|                | <u>N</u>         | <u>%</u> | <u>N</u> | <u>%</u> |
| Provider-Based |                  |          |          |          |
| HHA-Based      | 60               | 41.1     | 110      | 47.2     |
| Hospital-Based | 39               | 26.7     | 51       | 21.9     |
| SNF-Based      | 8                | 5.5      | 10       | 4.3      |
| Freestanding   | 39               | 26.7     | 62       | 26.6     |
| TOTAL          | 146              | 100.0    | 233      | 100.0    |

Source: HCFA/BERC Status Reports: (11/13/84, 10/1/85)

percent were HHA-based. However, 47 percent of certified hospices were HHA-based by October, 1985, compared to only 22 percent hospital-based (and 4 percent SNF-based) programs. Home care incentives in the law may have played some part in this outcome, but it should be remembered that the decision to participate reflects other factors as well. An earlier survey by the Inspector General of the Department of Health and Human Services detected interest in the Benefit among HHA's seeking to protect their shares in increasingly competitive markets and to defend against the financial implications of tighter controls over regular Medicare home health payments. Some independent hospices may have been discouraged by the anticipated "red tape", a barrier which was perhaps less serious for provider-based programs whose parent organizations regularly deal with public and private third party payers. Reasons for seeking or not seeking certification will be studied in next year's Hospice Benefit Evaluation report, making use of a survey of noncertified hospices that is still in progress.

#### 4.2        How many patients are being served?

In FY84, 2,473 patients for whom complete enrollment records are available elected the Hospice Benefit (2,005 died in FY84) this figure increased to 5,523 in 1985; 5,991, including some who enrolled in FY84, died in FY85. (Table 6) Enrollment began slowly and then grew steadily throughout 1984 and 1985, as newly-certified hospices entered the program.<sup>1</sup>

Most patients who died in hospice or after revocation of the Benefit stayed continuously in one program; seven patients exercised their option to transfer from one hospice to another. However, in FY85 a total of 35 patients

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<sup>1</sup>A smaller number of Benefit enrollees with complete claims data is used in this report in reimbursement analyses (1,582 in FY84 and 4,710 in FY85).

Table 6

FY 84, 85 Characteristics of Medicare Hospice Benefit Enrollees

| Category                                   | Number | Average Age | Percent Male | Percent White |
|--|--------|-------------|--------------|---------------|
| Total Enrolled in FY84 and:                | 2,473  | 74 years    | 51 percent   | 89 percent    |
| Died in Hospice (FY 1984)                  | 1,769  | 74 years    | 51 percent   | 89 percent    |
| Revoked Hospice Benefit and Died (FY 1984) | 236    | 74 years    | 51 percent   | 83 percent    |
| Died in Hospice (FY 1985)                  | 468    | 75 years    | 50 percent   | 92 percent    |
| Total Enrolled in FY85 and:                | 5,523  | 74 years    | 53 percent   | 90 percent    |
| Died in Hospice (FY 1985)                  | 5,262  | 74 years    | 53 percent   | 90 percent    |
| Revoked Hospice Benefit and Died (FY 1985) | 261    | 74 years    | 52 percent   | 90 percent    |

Source: FY84, 85 HCFA Hospice Benefit Enrollment File

left and reentered hospice before dying. As Table 7 shows, the average size of the "gap" between the first two hospice periods was 55 days. There were 327 patients who left hospice before death, about 5 percent of those who died in FY85.

Patients from freestanding hospices were somewhat more likely to leave the Benefit program before death (6.3 percent, compared to a 5.5 percent average). In addition, patients who left freestanding hospice programs were more likely to die in a hospital than other patients (53.2 percent, compared to an overall average of 45.9 percent).

Thus there are a reasonably large number of patients who did not follow the anticipated pattern of Benefit selection and death in hospice. During the HCFA hospice demonstration, 10 percent of Medicare-eligible patients were discharged alive. The relatively large proportion of live discharges experienced so far under the Benefit could affect overall cost savings of the Benefit program, if these patients were discharged into expensive hospital care. The small number of individuals who revoke and reelect the Benefit may also affect average savings estimates.

For enrollees who died in FY85, average length of enrollment (until death or termination of the Benefit) was 32.1 days,<sup>1</sup> with a median value of 20. This means that the distribution of stays was heavily concentrated around one to two months, but that there were a few long stay patients who pulled up

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<sup>1</sup>The difference between this and the FY84 estimate (29.3 days) may be due to actual increases in length of enrollment. It is more likely due to the fact that stays of patients admitted early in FY84 (or to any hospice immediately after certification) were shorter on average because many of these patients had already spent time in a hospice. Therefore the relatively shorter FY84 average enrollments are partly due to start-up phenomena. Moreover, patients enrolling and dying in FY84 had less opportunity for long enrollments because many certified hospices entered the programs late in the year.

Table 7

**FY 84, 85 Hospice Benefit Enrollment Periods:**  
**Length and Composition by Hospice Type**

| Length of Periods                                  | Overall         |                 | Free-Standing |                 | Hospital-Based |                 | SNF-Based     |               | HHA-Based     |                 |
|--|-----------------|-----------------|---------------|-----------------|----------------|-----------------|---------------|---------------|---------------|-----------------|
|  | FY 84           | FY 85           | FY 84         | FY 85           | FY 84          | FY 85           | FY 84         | FY 85         | FY 84         | FY 85           |
| Average length of enrollment<br>All enrollees      | 29.3<br>(2,005) | 32.1<br>(5,991) | 29.4<br>(892) | 32.5<br>(2,495) | 33.2<br>(353)  | 33.1<br>(1,413) | 22.7<br>(149) | 31.5<br>(255) | 28.3<br>(611) | 30.7<br>(1,828) |
| Average enrollment in<br>Benefit period 1:         | 27.2<br>(2,005) | 29.3<br>(5,991) | 27.3<br>(892) | 29.9<br>(2,495) | 30.5<br>(353)  | 29.8<br>(1,413) | 22.3<br>(149) | 28.2<br>(255) | 26.3<br>(611) | 28.1<br>(1,828) |
| Average enrollment in<br>Benefit period 2:         | 33.2<br>(121)   | 38.4<br>(409)   | 30.0<br>(61)  | 36.8<br>(170)   | 37.5<br>(24)   | 40.7<br>(106)   | 32.5<br>(2)   | 55.1<br>(13)  | 35.9<br>(34)  | 36.7<br>(120)   |
| Average enrollment in<br>Benefit period 3:         | 14.3<br>(8)     | 24.1<br>(40)    | 10.3<br>(4)   | 23.4<br>(9)     | 17.3<br>(3)    | 23.3<br>(15)    | --<br>(0)     | 30.0<br>(4)   | 21.0<br>(1)   | 23.6<br>(12)    |
| Average gap between<br>1 and 2:                    | 25.5<br>(13)    | 54.5<br>(32)    | 32.6<br>(7)   | 63.2<br>(16)    | 5.0<br>(1)     | 19.6<br>(5)     | --<br>(0)     | 47.5<br>(2)   | 19.8<br>(5)   | 60.1<br>(9)     |
| Average gap between<br>2 and 3:                    | --<br>(0)       | 109.0<br>(3)    | --<br>(0)     | --<br>(0)       | --<br>(0)      | 4.0<br>(1)      | --<br>(0)     | --<br>(0)     | --<br>(0)     | 161.5<br>(2)    |
| Average days before death:<br>left after period 1  | 25.1<br>(87)    | 52.5<br>(303)   | 23.0<br>(52)  | 44.7<br>(145)   | 14.0<br>(7)    | 64.7<br>(58)    | 41.0<br>(6)   | 80.6<br>(8)   | 29.2<br>(22)  | 54.7<br>(92)    |
| Average days before death:<br>left after period 2  | 28.6<br>(5)     | 56.5<br>(24)    | 46.5<br>(2)   | 45.8<br>(13)    | 10.0<br>(1)    | 44.0<br>(6)     | --<br>(0)     | --<br>(0)     | 20.0<br>(2)   | 99.2<br>(5)     |
| Average days before death:<br>left after period 3  | --<br>(0)       | --<br>(0)       | --<br>(0)     | --<br>(0)       | --<br>(0)      | --<br>(0)       | --<br>(0)     | --<br>(0)     | --<br>(0)     | --<br>(0)       |
| Average days before death<br>benefit was exhausted | --<br>(0)       | 51.2<br>(22)    | --<br>(0)     | 38.3<br>(4)     | --<br>(0)      | 55.0<br>(9)     | --<br>(0)     | 77.8<br>(4)   | --<br>(0)     | 33.4<br>(5)     |

Source: FY 84, 85 HCFA Hospice Benefit Enrollment File.

the average. Only 40 patients stayed into the third Benefit period; their average enrollment was 201 days. Average enrollment during the first year was shorter than averages for either home care or hospital-based hospice patients in the NHS. In part, this is due to the cutoff in payments under the Benefit at 210 days; patients' actual stays in hospice might not have changed, but the Benefit covers only part of hospice for the few with very long stays.

Patients who died in hospice had shorter stays than patients who revoked the Benefit (31.6 days, compared to 39.3 days); there also were other differences, such as relatively longer enrollments among cancer patients and female patients, that will be watched carefully over time (Table 8).

#### 4.3        Where are certified hospices located?

Medicare-certified hospices were most numerous in the Southeast (Region 4) and Midwest (Region 5) in FY85 (see Table 9). Of the hospices certified in FY85, 91 (39 percent) were in the South or Midwest. Between 1984 and 1985, the percentage of U.S. hospices certified increased. Table 9 uses NHO operating hospice programs as the universe of U.S. hospices, and shows an increase to 19 percent. The higher JCAH estimate for 1985 (roughly 1700 U.S. hospices) would yield a much smaller increase in percent certified (from 12 percent in FY84 to 14 percent in FY85). The Middle Atlantic States (Region 2) had the largest share in FY85 and Region 7 (Iowa, Kansas, Missouri and Nebraska) gained the smallest share.

As Table 10 shows, areas of the U.S. that have attracted certified hospice programs differ in certain respects from areas with only noncertified hospices or no hospice programs. Counties with certified hospices tend to be:

- larger in total population;
- more urbanized (measured by population density);
- higher in average income;

Table 8

FY 84, 85 Hospice Benefit Length of Enrollment,  
By Patient Characteristic: Enrollment Sample

| Characteristics                      | N     |       | Length of Enrollment |           |
|--------------------------------------|-------|-------|----------------------|-----------|
|                                      | FY 84 | FY 85 | FY 84                | FY 85     |
| Total                                | 2,005 | 5,991 | 29.3 days            | 32.1 days |
| Age                                  |       |       |                      |           |
| Less than 65                         | 125   | 334   | 32.0                 | 33.5      |
| 65 through 74                        | 1,001 | 2,899 | 29.4                 | 31.5      |
| 75 or more                           | 876   | 2,758 | 28.5                 | 32.5      |
| Sex                                  |       |       |                      |           |
| Male                                 | 1,026 | 3,171 | 27.8                 | 30.1      |
| Female                               | 976   | 2,820 | 30.6                 | 34.3      |
| Race                                 |       |       |                      |           |
| White                                | 1,773 | 5,423 | 29.7                 | 32.1      |
| Black                                | 162   | 385   | 24.6                 | 33.6      |
| Other                                | 19    | 47    | 21.8                 | 24.1      |
| Condition                            |       |       |                      |           |
| Cancer                               | 1,980 | 5,612 | 29.3                 | 32.1      |
| Non-Cancer                           | 25    | 375   | 25.7                 | 30.8      |
| Had no gaps                          | 1,992 | 5,956 | 29.1                 | 31.8      |
| Had gap between<br>benefit periods   | 13    | 35    | 48.5                 | 77.9      |
| Died in hospice                      | 1,913 | 5,664 | 29.2                 | 31.6      |
| Left hospice,<br>died out of hospice | 92    | 327   | 31.4                 | 39.3      |

Source: FY 84, 85 HCFA Hospice Benefit Patient File: Enrollment Sample

Table 9

Operating Hospice Programs, by Region,  
Certification Status: 1984-1985

| Region                                | November 13, 1984 |             |            | October 1, 1985 |             |            |
|---------------------------------------|-------------------|-------------|------------|-----------------|-------------|------------|
|                                       | Certified         | Total       | Certified  | Total           | Certified   | Total      |
| 1 (CT, ME, MA, NH,<br>RI, VT)         | 6                 | 134         | .04        | 16              | 134         | .12        |
| 2 (NJ, NY, PR)                        | 19                | 79          | .24        | 28              | 81          | .35        |
| 3 (DE, DC, MD, PA,<br>VA, WV)         | 15                | 142         | .11        | 22              | 149         | .15        |
| 4 (AL, FL, GA, KY,<br>MS, NC, SC, TN) | 36                | 159         | .23        | 50              | 161         | .31        |
| 5 (IL, IN, MI, MN,<br>OH, WI)         | 20                | 265         | .08        | 41              | 269         | .15        |
| 6 (AR, LA, NM, OK,<br>TX)             | 10                | 76          | .13        | 17              | 76          | .22        |
| 7 (IA, KS, MO, NE)                    | 7                 | 87          | .08        | 10              | 87          | .11        |
| 8 (CO, MT, ND, SD,<br>UT, WY)         | 7                 | 62          | .11        | 12              | 65          | .18        |
| 9 (AZ, CA, NV)                        | 15                | 144         | .10        | 21              | 146         | .14        |
| 10 (AK, ID, OR, WA)                   | 11                | 70          | .16        | 16              | 71          | .23        |
| <b>TOTAL</b>                          | <b>146</b>        | <b>1218</b> | <b>.12</b> | <b>233</b>      | <b>1239</b> | <b>.19</b> |

Source: HCFA Provider of Service File; National Hospice Organization Guide to the Nation's Hospices.

Table 10

Characteristics of U.S. Counties by Availability of Hospice Care  
(1982)

| Characteristics  | One or More Certified Hospice (FY84) | Only Noncertified Hospice(s) | No. Hospices |
|--|--------------------------------------|------------------------------|--------------|
| County Population (000s)   | 555                                  | 144                          | 29           |
| Population Density<br>(Population per square mile)   | 1661                                 | 412                          | 56           |
| Number of CT Scanners in County  | 3.76                                 | 0.79                         | 0.06         |
| Mean Per Capita Income   | \$9,816                              | \$8,739                      | \$7,011      |
| Average Medicare Cancer Deaths<br>in Hospital Per Year Per 100,000<br>Population Aged 65 and Older | 400.5                                | 467.5                        | 494.5        |
| Cancer Discharges by Principal<br>Cancer Site  |                                      |                              |              |
| Colon  | 31%                                  | 30%                          | 28%          |
| Lung   | 28                                   | 28                           | 32           |
| Breast   | 5                                    | 5                            | 4            |
| Prostate   | 11                                   | 9                            | 11           |
| Urinary  | 5                                    | 5                            | 5            |
| Leukemia   | 5                                    | 7                            | 5            |
| Other cancer   | 14                                   | 16                           | 15           |
| Average Annual Rate of Growth in<br>Hospital Charges for Deceased<br>Cancer Patients (1979-1982)   | 15.8%                                | 16.8%                        | 14.2%        |
| Average Length of Hospital<br>Stay (Deceased Cancer Discharge)                                     | 15.4 days                            | 14.5 days                    | 15.6 days    |
| Average ICU Days Per Deceased<br>Cancer Discharge  | 1.030 days                           | 0.88 days                    | 0.79 days    |
| Percent of Deceased Cancer Discharges  |                                      |                              |              |
| Age 74+  | 44%                                  | 43%                          | 45%          |
| Male   | 54%                                  | 57%                          | 60%          |
| White  | 88%                                  | 91%                          | 87%          |
| Deceased in Medical School<br>Affiliated Hospital  | 47%                                  | 45%                          | 29%          |
| Deceased Underwent Surgery   | 21%                                  | 21%                          | 18%          |

Source: HCFA Hospice Evaluation County File.

- more "intensive" in the type of hospital care provided dying cancer patients (measured by ICU days per discharge, percent undergoing surgery); and
- more access to sophisticated health care technology (percent dying in medical school-affiliated hospital, number of CT scanners).

In addition, counties that attracted either certified or noncertified hospices experienced somewhat more rapid inflation in hospital charges for deceased cancer patients between 1979-1982 than counties without hospices. Medicare cancer death rates in hospital were lower in certified hospice counties than in other areas.

These findings suggest that demographic and socioeconomic factors may have played an important role in the geographical pattern of hospice industry growth and in the decision to become Medicare certified. Next year's report will examine this issue in greater detail, using data from three years' experience under the Benefit.

#### 4.4 What was the experience of hospices that applied for certification?

Evidence regarding hospices' experience in applying for Medicare certification is fragmentary and anecdotal at best. The only current information on how hospices coped with this process comes from reports submitted to HCFA by demonstration hospices that elected, in the closing months of the demonstration, to apply for certification; impressions presented have come from those reports and should be treated as case studies that may not reflect the experience of other hospices.

Those hospices that applied for certification often encountered barriers due to program implementation problems and occasionally to community hostility toward the Benefit; as one hospice reported, "one entire year was not long enough to prepare for implementation in our community."

For some hospices, the lag between planning and billing as a certified provider exceeded one year. As one administrator noted:

In August of 1983, we began discussions with both local hospitals for inpatient contracts. In addition, we had informal discussions with a local nursing home for respite services. We also began an educational process with community physicians on how the legislation differed from the demonstration effort. It was a somewhat frustrating time in that final regulations were not available until 1984 so much of the discussion was based on theory, not fact. Once the regulations were received, contract negotiations continued and resulted in firm commitments from both hospitals primarily because of their support of the concept of hospice and despite the financial risk to them. It was not until March of 1984 that the state surveying agency was ready to do the site visit and evaluate our program. Although this was all completed in March, it wasn't until seven months later that we were notified that our program was certified - effective Oct. 1, 1984. Even then, many questions were left unanswered about program implementation, policy, billing, etc. In December of 1984 the fiscal intermediary held a training session for the five certified hospice programs, out of which many questions were generated. Answers to those questions arrived in June, 1985 (see attached memo).

In addition to policy questions and problems, the fiscal intermediary was not ready to process claims which aggravated the already existing problem of inadequate case flow. After multiple phone calls, the intermediary agreed to receive bills and our first payment was received in March of 1985. (Visiting Nurse Association. Burlington, VT. Final Report, Hospice Demonstration Project. September 17, 1985).

Although the experiences of these hospices may not have been representative, several important issues are raised that deserve continued attention:

Physician hostility toward the Benefit. Physician attitudes toward hospice have been conditioned by the traditional code of medical ethics that stresses aggressive curative therapy (Veatch and Tai, 1980). Attitudes and decision-making patterns have changed. More physicians have been willing to delegate the decision to discontinue care to the patient's family (Neu and Kjellstrand, 1986). However, physician hostility remains a barrier to the

growth of the hospice concept. One report noted that ". . . we are experiencing anger from physicians who question our knowledge/experience or our right to suggest alternatives or both, when we not only question hospitalization but refuse to authorize it," (Community Home Health Care. Final Report, Hospice Demonstration Project, May 1, 1985) Language in the law and in regulations creates the potential for conflict between interdisciplinary teams and attending physicians over management of patients' care; apparently, this conflict has materialized in some areas. Physicians who are not part of the hospice team are further separated from the process by the hospice reimbursement methodology; attending physicians bill separately under Medicare Part B, as they commonly do for care delivered in hospitals. It is not clear how these conflicts will be resolved; however, the same report that spoke of physicians' anger also implied that more effective communication would possibly have ameliorated the situation. Other hospices seconded this view that public education could be helpful in winning physician acceptance and increasing referrals.

Reluctance of patients and families to elect the Benefit. As one respondent pointed out:

We have found the more explicit (than was used in the demonstration) informed consent requirement to be somewhat difficult for clients. In addition, the election process is frightening to some because of their fear of what it is they are giving up. The firm commitment to home care is also frightening particularly if the primary care provider is an elderly spouse and who naturally finds it difficult to foresee and anticipate what the final days may be like. (VNA, Burlington, VT, op. cit.)

Public education might overcome some fears and attract more elections, but there are certain essential features of the Benefit that seem likely to discourage participation by patients who lack adequate home supports regardless of how well-informed physicians and potential hospice users become.

Conflict with hospitals. The Medicare Hospice Benefit was implemented during the first full year of Medicare prospective payment for hospital care. Some observers had speculated that hospitals under PPS might try to "dump" complex Medicare cases, discharging them to other providers such as home health agencies, nursing homes and hospices. One reporting hospice, after a year's experience, noted a declining length of stay and an increase in the severity of patients in its own program, concluding that ". . . the DRG implementation in hospitals and our reputation for good care have resulted in an increasingly acutely ill population of referrals." This pattern has two implications, according to this hospice: first, ". . . hospice intervention becomes crisis intervention. . . .", losing the unique quality hospice has to prepare families and patients for death; second, short complex stays are expensive and place the hospice's Medicare Benefit program under severe financial strain, (Community Home Health Care. Final Report, Hospice Demonstration Project. May 1, 1985).

Another implication of hospital reimbursement reform appears to be an incentive for some hospitals to organize their own affiliated long term care units, to which discharged patients can be referred. One reporting hospice viewed with some alarm the intentions of a nearby hospital to organize its own hospice program. It is not clear whether this observation represents a trend; as we noted above, hospital-based hospices are now more numerous among U.S. hospices than any other type. Whether or not newly-formed hospital-based hospices would be more likely to apply for certification than existing programs have been remains to be seen.

Conclusion

During the first two years of the Medicare Hospice Benefit, the proportion of U.S. operating hospices certified increased from 12 percent to a percentage between 14 and 20 percent, depending on what one assumes to be the total size of the industry. Growth tended to occur in wealthy, urbanized areas that had experienced relatively rapid hospital charge inflation. Despite their majority status in the industry, hospital-based hospice programs were less likely to seek certification than HHA-based or freestanding programs.

These developments, and evidence from the JCAH survey presented earlier in Section 3.0, lend credence to arguments that the Benefit favors hospices that can directly provide a range of home health services and hospices that are relatively comfortable with the demands for accountability built into the provider-Medicare payer relationship. However, it would be premature to argue that the Medicare Hospice Benefit has pushed the whole industry in one direction, based on the experience of only two years. There are still many hospices that have decided, for the time being, that certification is not an attractive option. Factors associated with hospice industry growth will be examined again in next years' report, using data from three years of the Hospice Benefit.

Hospice advocates have used cost effectiveness as an argument for adding hospice benefits to public and private health insurance. The argument has intuitive appeal. With some exceptions, hospices in America stress home care which, from a third party payer's perspective, is nearly always less expensive than hospitalization. The hospice clinical intervention is palliative rather than curative; palliative care should require fewer costly ancillary services than aggressive curative therapies, and therefore hospice inpatient care, when required, is also less expensive than curative care.

The relative "effectiveness" of hospice is difficult to evaluate. Hospice is designed to improve the quality of the patient's last days of life and to help families cope with death. Researchers have developed summary indices of the quality of life to measure the outcomes of health care interventions; however, it is hard to compare hospice and conventional care in terms of quality, because the dominant goals of conventional aggressive therapy (lengthening life, effecting remission, satisfying relatives and health care professionals that every effort has been made to conquer the disease) are so different from hospice goals. If the stereotyped aggressive conventional therapy places primary emphasis on cure and remission, its effectiveness in curing should not be compared to hospice, with its emphasis on pain and symptom control. It would be unrealistic to assume that conventional, nonhospice approaches to treating advanced cancer have been unaffected by the changes in attitudes that have led to the increased popularity of hospice care.

Because of these uncertainties, the cost side of the cost effectiveness equation has received considerable attention in the research literature,

but researchers have only begun to study qualitative outcomes. In this section, previous research on questions of hospice payment, cost and savings is reviewed. Then Medicare hospice charges and payments under the Benefit are compared to Medicare conventional care charges and payments.

#### 5.1        Who pays for Hospice care?

Even if all of the costs of caring for hospice patients were lower than conventional care costs, some payers might enjoy savings while others do not. Because payer coverage and payment methods are different among settings of care, the burden of payment can be shifted from one payer to another. Medicare's Hospice Benefit embodies a strategy for placement in the home, through a rate and cap payment structure that penalizes "excessive" inpatient utilization.

A home-oriented strategy could shift part of the payment burden from Medicare and other third party payers to the patient and family. Even though savings to Medicare in hospital costs might be demonstrable, "hidden" costs in the form of out-of-pocket expenditure for physicians, drugs, medical supplies and copayments for services might be higher for patients in hospice than they are in nonhospice settings. In addition, the true cost of hospice care includes time invested by primary care givers and other family and friends, who together can provide a supportive home environment. These indirect costs are borne by the family. This section examines evidence on the question of how hospice costs have been divided among private third-party payers, public contributors, patients and their families.

#### Third party payers

Federal funding contributed to some hospices' operating expenditures in the past, even before passage of the Benefit. An early GAO study indicated that Medicare and Medicaid payments covered slightly more than one quarter of

the total operating expenses (averaging around \$100 thousand per year) of 19 hospices. (GAO, 1979) All federal money in the sample hospices went to facility-based hospices, and in fact only 3 of the 19 hospices received Medicare reimbursement at all. Thus, although Medicare patients comprise about 60 percent of all hospice patients, 16 hospices in the GAO sample received no direct Medicare or Medicaid reimbursement.

JCAH (1987) data show that Medicare-certified hospices depended heavily for revenue both on the Benefit and on Medicare's regular Part A home health benefits. Only 10 percent of certified hospices surveyed received no Benefit payments in 1985. Thirty-three percent received 70 percent or more of total revenues from the Benefit. Six percent relied on part A home health payments for 70 percent or more of revenue. In contrast, noncertified hospices derived most of their revenue from donations; twenty-two percent earned 70 percent or more from this source. Medicare contributed to revenues of noncertified hospices through the regular Part A home health benefit. Thirteen percent of noncertified hospices depended on this source for 70 percent or more of total revenue.

#### Out-of-pocket family and patient expenditures

One of the reasons Congress added the Hospice Benefit was to fill gaps in traditional Medicare coverage (particularly in some kinds of home health services and outpatient drugs), payments for which hospice and other terminally-ill patients have been liable in the past. Information regarding out-of-pocket liability reported here is based wholly on HCFA demonstration data. Because of the expense associated with collecting out-of-pocket expenditure data directly from Hospice Beneficiaries, no information on patient spending under the Benefit will be gathered in this Evaluation.

HCFA demonstration hospice patients' out-of-pocket expenditures for drugs, supplies and equipment were generally higher than expenditures of conventional care patients; self-payment of other medical expenses, however, was higher among conventional care patients. Differences by hospice type reflect the greater burden of outpatient drug supply and equipment costs on patients cared for at home; expenditures per day were 17 times higher for non-bedded hospice than conventional care patients, but only 7 times higher for patients of bedded hospices.

HCFA's hospice demonstration program paid generously for hospice services, and the effects can be seen in out-of-pocket spending. Medicare beneficiaries not enrolled in the HCFA demonstration program paid more out-of-pocket for all hospice medical expenses than did demonstration patients. Medicare patients in non-participating, non-bedded hospices were more likely to incur expenses than their counterparts in the demonstration (48 versus 41 percent). In addition, the former paid more per day (\$10) than the latter (\$7). The difference was even more dramatic in bedded hospices, where Medicare demonstration patients paid \$5 per day out of pocket, compared to \$42 paid by Medicare patients in nondemonstration hospices. Medicare conventional care patients paid the most out of pocket, at a rate of about \$46 per day.

Patient characteristics had some effect on total out-of-pocket spending. Regardless of hospice type, out-of-pocket spending was higher for the more impaired patients (relatively low functional ability at intake and living alone). The level of out-of-pocket spending did not vary greatly with family income; in fact, relatively low income hospice patients paid a slightly higher percentage of family incomes for care than wealthy patients, which suggests that most unreimbursed expenses were probably not for luxuries. The specialty of a patient's attending physician affected spending; expenditures

incurred by patients of primary care physicians were only 48 percent of expenditures by patients of specialists.

There is much diversity in out-of-pocket expense that cannot be explained by patients' medical condition, socioeconomic status or the type of hospice program entered. For example, although the average level of spending per day among hospice patients outside the HCFA demonstration was \$27 (\$1377 per patient), the median or middle value was \$0.60 per day. This shows that even though half of the patients spent \$0.60 or less, a few spent large amounts, as much as \$800 to \$1000 (usually over very short enrollment periods).

#### Informal supports

There are costs of maintaining a patient at home that are never directly paid by the patient, family or third parties. The most significant of these indirect costs is foregone income of caregivers, who provide unpaid care and support sometimes at the expense of their own jobs. Concerns about the mix of formal and informal care reflect two perspectives. On one hand, if informal care substitutes for formal reimbursable services, some fear that both direct and indirect costs will be shifted from third party payers onto the patients' family. On the other hand, if formal services are substituted for informal services, some fear that the hospice approach, which is philosophically grounded in volunteerism and family-centered care, will erode.

A recent study of informal care in hospice indicates that, although both kinds of substitution occur, substitution of informal for formal care is the more common occurrence (Mor, Laliberte *et al.*, 1985 unpublished). Throughout the last weeks of life, 10 to 14 hours of informal care were provided each day, representing over 70 percent of the total hours of care the

average patient received. However, the degree of involvement varied considerably among families. For example, some patients who used inpatient care intensively received about 3 hours of informal care per day; for whatever reason, the home support system could not cope with the extensive care needs of this group of terminal cancer patients, who had to depend principally on institutional care.

The total hours of direct patient care per day that hospice patients received from both formal and informal sources stayed remarkably constant at a level of 13 to 14 hours throughout the enrollment period, rising somewhat toward the patient's death as care increased from both sources. Patients received the most hours of formal services both at intake, when assessment and planning are done, and toward the end of life, when inpatient care or intensive, continuous care at home may be needed.

The indirect cost of providing informal care can be considerable. Figures from the HCFA demonstration show that families lost about \$480 in income when the primary caregiver remained employed part-time, and \$2,400 when she/he quit work altogether to care for the dying patient. Differences between hospice and conventional care families in dollar costs of time lost in this sample were not large. More important, primary caregivers of non-bedded hospice patients were more likely to quit work (33 percent) than were hospital-based hospice patients or conventional care patients (22 and 24 percent respectively).

If a non-bedded hospice family spent the average \$1,377 out-of-pocket costs and incurred the average lost income of \$2,400, its total direct and indirect cost of care (\$3,777) represents over half of total costs paid by third parties. Conventional care families of Medicare beneficiaries probably spent more in total dollars, even though caregivers were less likely to leave

their jobs, because these families spent more out-of-pocket than hospice families. However, the burden was proportionately lower for conventional care families, whose third party-reimbursed costs of care were higher than they were for non-bedded hospice patients.

5.2        Is hospice less expensive than conventional care? Evidence from previous research

Most studies of hospice costs conducted before implementation of the Medicare Benefit have concluded that hospice care is, in general, no more expensive than conventional treatment of terminally ill patients (Kane, et al., 1984; Spector and Mor, 1984); some studies have claimed hospice is considerably less expensive (Brooks and Smyth-Staruch, 1984; Bloom and Kissick, 1980). An important exception to this rule was HCFA's Office of the Actuary, which predicted that the Hospice Benefit would not save Medicare reimbursements. This study is discussed below.

These studies are difficult to compare and evaluate. Aside from differences due to the various years during which data were collected, researchers use different dollar measures (charges, reimbursements, imputed costs), different definitions of what are "comparable" hospice and conventional care patients, different types of hospice programs and different definitions of what constitutes a hospice. Nonetheless the general evidence favors the conclusion that hospice costs less than non-hospice care.

The total cost of treating a patient in hospice has been estimated to be as low as \$485 (Kassakian et al., 1979) (home care only during the last month of life for 23 patients) and as high as \$15,263 (Kane et al., 1984). Estimates from recent studies (Narkiewicz, 1986; McCusker and Stoddard, 1985; Oji-McNair, 1985) tend to be concentrated in a range of \$6,000 to \$9,000. The

cost per hospice day ranges from \$14 (1983 \$) to \$216 (1983 \$), with most in the range of \$100 to \$150.

NHS data showed that costs per day in hospice were higher:

- for patients admitted with relatively severe functional impairment;
- for patients with relatively short lengths of hospice stay;
- for patients with cancer diagnoses;
- for patients with relatively limited home support;
- for patients admitted to bedded hospices (that furnish inpatient care directly, rather than by arrangement or contract with another provider).

Medicare Part A payments for treating terminally-ill cancer patients in non-hospice settings during the last year of life had been estimated in the Medicare hospice demonstration evaluation to be \$14,799. Reimbursements for a more representative sample of cancer decedents taken from Medicare's Continuous History File for 1979 were somewhat lower, at \$10,989 in 1982 dollars, split 80/20 percent between Parts A and B (HCFA, internal memo, 1986). Most studies have shown costs of the terminally-ill to be fairly constant until the last three months of life. In the NHS patient sample, conventional care patients' costs rose from \$24 per day in the fourth month before death to \$203 per day in the last month (Kidder, 1984). All studies have agreed that over half of total costs (or reimbursements) comes in the last three months of life, ranging from 75 percent (Spector and Mor, Narkiewicz) to 55 percent (Lubitz and Prihoda).

### 5.3        Evidence on Cost Components in Hospice and Conventional Care

This section touches lightly on NHS findings regarding inpatient and home care utilization; patient-level claims data for these components are analyzed more fully elsewhere in this report. More attention is paid to

related research regarding services for which Benefit data at the patient level are not readily available: nursing home services, physician services, outpatient drugs, supplies and equipment.

#### Inpatient Services

NHS data show that average inpatient reimbursements in hospice were lower than in conventional care for two reasons; average days hospitalized were fewer, and average ancillary costs per day were lower in hospice.

#### Home Care Services

Hospice home care reimbursements measured in the NHS were higher than conventional care costs in the last months of life, because hospice patients received more and longer home visits than did conventional care patients. In non-bedded NHS hospices, there was evidence that some home care services were substituted for inpatient services. However, bedded hospices apparently added home care services to an average level of inpatient utilization considerably higher than the average in non-bedded hospices.

#### Nursing Home Services

Nursing home care is apparently little used in the last stages of terminal illness. Medicare demonstration data showed that conventional care patients used more Medicare-reimbursed skilled nursing facility care, incurring about \$52 of reimbursements in the last month of life, compared to \$24 for hospice patients. These represented less than one percent of total reimbursements for both groups. Other studies based on data with more complete payer coverage reach the same conclusion. Spector and Mor (1984) estimate that average nursing home reimbursements in the last month of life of patients with both Medicare and Blue Cross/Blue Shield coverage are less than 3 percent of the total reimbursements. SNF care represented one percent or

less of total charges recorded in studies by Narkiewicz (1986) and McCusker and Stoddard (1985).

Medicare does not reimburse most of the nursing home care used by beneficiaries. In fact, Medicaid pays for a large part of nursing home services used by the Medicare-eligible population. Data from New York, collected as part of the Hospice Benefit Evaluation, show that dying Medicaid patients used more Medicaid-reimbursed hospital care and fewer nursing home service as death approaches. Over the entire last year of life, however, nearly 70 percent of total Medicaid reimbursements went to nursing home providers (Klingman, 1985).

HCFA analysts have merged 1980-81 Medicare and Medicaid data for four states (New York, California, Tennessee and Georgia); the Hospice Benefit Evaluation used records of patients who died of cancer in 1981 to study the share of nursing home reimbursement during the last year of life. For patients with a full year of information, Medicaid-reimbursed nursing home care represented 12 percent of the total reimbursements of \$21,069 (Medicare SNF payments were only 0.6 percent). Hospitalization payments from both sources were about 60 percent of the total. For patients with only one month of data (the last month of life), nursing home payments dropped to 8 percent, whereas inpatient payments increase to 82 percent of the total.

#### Physician Services

Conventional care patients in the HCFA demonstration paid more for the services of attending physicians than did hospice patients; NHS estimates show a difference of \$9 per day. Oji-McNair (1985), however, found no difference; physician/outpatient expenditure constituted seven percent of the total in both settings.

The merged Medicare/Medicaid data show that physician/outpatient reimbursements equaled 20 percent of total reimbursement in the last year of life. Medicare Part B payments accounted for 15 percent. In the final month, the physician/outpatient percentage dropped to 9 percent (7 percent was paid by Medicare).

Outpatient Drugs, Supplies and Equipment

Although preventive use of analgesic drugs has been a central tenet of hospice philosophy, little research has been done to compare costs of outpatient drugs in hospice and conventional care. There are no data to compare drug costs both in inpatient and home settings, since Medicare Benefit drug costs are included in the average payment rates. Data on drug costs come from certified hospice provider cost reports. These may represent drugs supplied to patients in an inpatient or outpatient setting. The Medicare demonstration produced some information about drugs dispensed to patients on an outpatient basis and paid for out-of-pocket which suggests that hospice patients spent more than conventional care patients. Non-bedded hospice patients spent about \$1.82 per day, compared to \$0.73 per day for bedded hospice and \$0.11 per day for conventional care patients.

Medicaid payments during the last year of life for prescription outpatient drugs used in 1981 by non-hospice cancer decedents in New York State averaged \$0.28 per day. Payments for prescription drugs fell from the sixth month (\$0.33 per day) to the last month (\$0.13). This pattern does not necessarily mean that drug utilization declined; in part, it probably reflects increased rates of hospitalization characteristic of the final months. Hospital drug charges are part of total inpatient charges, and cannot be separated out in the Medicaid claims data.

Prescription drugs were 0.9 percent of total Medicare and Medicaid reimbursements for jointly eligible cancer patients over the last year of life. The percentage declined throughout the year. During the last months, when many patients were hospitalized, Medicaid payments for drugs were 0.2 percent of total reimbursements.

#### 5.4 Costs and Medicare Reimbursements to Hospice Benefit and Conventional Care Patients

This section presents evidence on the costs of treating terminally-ill Medicare patients since implementation of the Benefit. Comparisons are made across patients (categorized by age, sex, race) and hospice types (hospital-, SNF-, HHA-based and freestanding), as well as between hospice and conventional care. Measures used include charges, Benefit and Medicare Part A reimbursements and, for certain service components, line item costs from Medicare-certified hospice cost reports. Patient level estimates of Benefit and Part A charges and payments come from two samples:

- Hospice Benefit enrollees who died in FY84 or FY85 and had a valid date of death, and complete claims data (including Benefit and/or Part A claims) spanning the enrollment period. Totals of 1,582 (FY84) and 4,710 (FY85) enrollees met these criteria (out of totals in each year of 2,005 and 5,991 respectively).
- A sample of 7,467 conventional care patients, chosen randomly from counties with and without hospice services, who died in FY85, had a valid date of death and at least one Medicare inpatient claim which recorded a diagnosis of cancer or other life-threatening condition, within the two-year period before death. Only cancer patients were included in this year's comparative analyses.

Analyses based on three full years of data from hospice and conventional care patients, including analyses of non-cancer costs, will be included in the final Evaluation Report in 1988.

How much did Medicare spend on Hospice Benefit enrollees in the last two years of life?

Total reimbursements for Benefit enrollees (including both Benefit and regular Part A) increased from FY84 to FY85, but regular Part A reimbursements declined. Table 11 shows that most Part A reimbursements (98 percent in FY85) were incurred either before enrollment in the Benefit or after disenrollment (one percent), for those who die after leaving hospice.

Average hospice reimbursements per patient increased by about 16 percent, (from \$1,798 to \$2,078), at a rate considerably higher than the rate of medical care cost inflation (6.2 percent between 1984 and 1985). At the same time, total Part A reimbursement for Hospice Beneficiaries, (before, during and after Benefit enrollment) dropped slightly from \$13,403 in the last two years of life to \$12,947. It is too soon to tell whether or not this represents a trend associated, perhaps, with decreasing hospital payments under PPS. Longer average hospice enrollments in FY85 which, as noted earlier, may be a result of increased numbers of certified hospices, could help account for this decline, if Benefit reimbursements were substituting for more regular Part A reimbursements. FY86 reimbursement estimates in next year's report should provide further evidence on this point.

How do Hospice Benefit charges vary across hospice types?

Although there is no information currently available to the Evaluation on the types of arrangements Medicare-certified hospices made to provide inpatient care, estimates of average charges<sup>1</sup> presented in Table 12

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<sup>1</sup>Although Medicare does not pay charges, many Hospice Benefit claims submitted in FY84 contained no information on reimbursements. In order to compare "prices" of providing Beneficiaries with services across hospice types, we chose to use the relatively more complete data on charges. Data reported in the FY84 Technical Report of this Evaluation show similar patterns of charge and reimbursement variation across hospice types.

Table 11

**FY 84, 85 Medicare Reimbursements for Terminally Ill Hospice Patients**  
**During the Last Two Years of Life**

| Hospice Plus<br>Part A        | Full Two-<br>Year Period |                   | Before Hospice<br>Enrollment |                   | Hospice<br>Benefit<br>Period 1 |                  | Inter-Benefit<br>Gap 1 |               | Hospice<br>Benefit<br>Period 2 |                | Inter-Benefit<br>Gap 2 |              | Hospice<br>Benefit<br>Period 3 |               | Disenrollment/<br>Death Gap |                |   |
|-------------------------------|--------------------------|-------------------|------------------------------|-------------------|--------------------------------|------------------|------------------------|---------------|--------------------------------|----------------|------------------------|--------------|--------------------------------|---------------|-----------------------------|----------------|---|
|                               | FY 84                    | FY 85             | FY 84                        | FY 85             | FY 84                          | FY 85            | FY 84                  | FY 85         | FY 84                          | FY 85          | FY 84                  | FY 85        | FY 84                          | FY 85         | FY 84                       | FY 85          |   |
|                               |                          |                   |                              |                   |                                |                  |                        |               |                                |                |                        |              |                                |               |                             |                |   |
| <b>Hospice Benefit</b>        |                          |                   |                              |                   |                                |                  |                        |               |                                |                |                        |              |                                |               |                             |                |   |
| Total<br>(000s of dollars)    | \$2,844.4                | \$9,785.4         | 0                            | 0                 | \$2,762.7                      | \$9,336.6        | 0                      | 0             | \$79.3                         | \$416.8        | 0                      | 0            | \$2.3                          | \$32.0        | 0                           | 0              | 0 |
| Per Patient(dollars)<br>(N= ) | 1,798<br>(1,582)         | 2,078<br>(4,710)  | 0                            | 0                 | 1,746<br>(1,582)               | 1,982<br>(4,710) | 0                      | 0             | 2,558<br>(31)                  | 2,998<br>(139) | 0                      | 0            | 1,163<br>(2)                   | 1,687<br>(19) | 0                           | 0              | 0 |
| <b>Medicare Part A</b>        |                          |                   |                              |                   |                                |                  |                        |               |                                |                |                        |              |                                |               |                             |                |   |
| Total<br>(000s of dollars)    | 19,100.5                 | 56,373.3          | 18,679.1                     | 55,146.7          | 153.0                          | 488.5            | 30.7                   | 58.8          | 2.3                            | 7.6            | 0                      | 2.2          | 0                              | 0             | 235.4                       | 669.4          |   |
| Per Patient(dollars)<br>(N= ) | 13,403<br>(1,425)        | 12,947<br>(4,354) | 13,164<br>(1,419)            | 12,645<br>(4,361) | 1,889<br>(81)                  | 2,210<br>(221)   | 3,840<br>(8)           | 4,521<br>(13) | 2,294<br>(1)                   | 1,900<br>(4)   | 0                      | 2,219<br>(1) | 0                              | 0             | 4,441<br>(53)               | 4,264<br>(157) |   |
| <b>Hospice Plus Part A</b>    |                          |                   |                              |                   |                                |                  |                        |               |                                |                |                        |              |                                |               |                             |                |   |
| Total<br>(000s of dollars)    | 21,944.9                 | 66,158.7          | 18,679.1                     | 55,146.7          | 2,915.8                        | 9,825.1          | 30.7                   | 58.8          | 81.6                           | 424.4          | 0                      | 2.2          | 2.3                            | 32.0          | 235.4                       | 669.4          |   |
| Per Patient(dollars)<br>(N= ) | 13,854<br>(1,584)        | 14,046<br>(4,710) | 13,164<br>(1,419)            | 12,645<br>(4,361) | 1,843<br>(1,582)               | 2,086<br>(4,710) | 3,840<br>(8)           | 4,521<br>(13) | 2,632<br>(31)                  | 3,053<br>(139) | 0                      | 2,219<br>(1) | 1,163<br>(2)                   | 1,687<br>(19) | 4,441<br>(53)               | 4,347<br>(154) |   |

Source: FY 84, 85 HCFA Hospice Benefit Patient File: Utilization Samples.

Table 12

FY 84, 85 Hospice Benefit Charges Per Patient by Service and Hospice Type  
Utilization Sample

| Service                | All        |            | Free-Standing |            | Hospital-Based |            | SNF-Based  |            | HHA-Based  |            |
|------------------------|------------|------------|---------------|------------|----------------|------------|------------|------------|------------|------------|
|                        | FY 84      | FY 85      | FY 84         | FY 85      | FY 84          | FY 85      | FY 84      | FY 85      | FY 84      | FY 85      |
| Total                  | \$1,842.97 | \$2,202.13 | \$1,415.44    | \$1,629.13 | \$2,364.33     | \$3,052.43 | \$2,120.91 | \$3,443.05 | \$2,154.76 | \$1,930.61 |
| Routine Home Care      | 1,017.61   | 1,258.48   | 955.03        | 1,007.02   | 1,474.17       | 1,657.25   | 940.50     | 1,497.10   | 873.57     | 1,166.73   |
| Continuous Care        | 175.57     | 138.74     | 120.17        | 119.86     | 136.36         | 75.66      | 9.80       | 31.30      | 339.50     | 233.16     |
| Inpatient Respite Care | 4.97       | 5.26       | 1.23          | 2.09       | 18.28          | 9.62       | 6.48       | 6.89       | 2.81       | 4.89       |
| General Inpatient Care | 611.39     | 769.59     | 309.01        | 449.65     | 671.47         | 1,290.48   | 1,151.10   | 1,898.13   | 991.87     | 507.05     |
| Physician Services     | 33.41      | 30.07      | 30.00         | 50.50      | 64.05          | 19.43      | 13.02      | 9.62       | 27.00      | 18.77      |

Source: FY 84, 85 HCFA Hospice Benefit Utilization Files.

tend to confirm findings from the NHS: patients in provider-based hospices that are most likely to have the capacity to supply inpatient care directly (hospital- and SNF-based hospices) generally incurred higher charges per patient and per day than patients in hospices that past research has shown often contract for inpatient care (HHA-based and many freestanding hospices). Freestanding hospice patients incurred the lowest average charges in both FY84 and 85. SNF-based patients incurred the highest charges per day in both years (roughly 50 percent above freestanding charges).

Medicare-certified hospice providers had no difficulty meeting the aggregate per patient reimbursement cap during FY84 and 85. As Table 13 shows, no hospice exceeded the cap, originally \$6500 per patient and annually adjusted for inflation, in either year. Past research predicts that hospital-based hospices would be most at risk of exceeding the cap. However, only one hospice, with an average of \$6,671 per patient, even approached the cap in FY85. The single HHA-based hospice that incurred average charges over \$6,000 in FY84 (at \$6,298 per patient) did not bill Medicare in FY85.

There is an unexplained decline between FY84 and 85 in total and per diem charges for patients in HHA-based hospices. Total charges declined by 11 percent and, because the average stay was longer in FY85, per diem charges declined by 18 percent. Table 14 suggests that these lower charges may have been partly due to a change in the relative proportions of inpatient and home care provided in HHA-based hospices. Routine home days of the average HHA-based hospice patient increased 22 percent between FY84 and 85, while the more costly general inpatient days declined by 40 percent. In contrast, the average hospital-based hospice patient used 11 percent fewer home days but 71 percent more inpatient days. HHA-based patients also used fewer days of costly continuous care and, as Table 12 shows, fewer Benefit-reimbursed

Table 13

FY84, 85 Medicare Certified Hospice Providers Conformance to Reimbursement Cap

| Hospice Type   | Minimum Average Charge |       | Maximum Average Charge |         | Number \$6500 <sup>1</sup> or greater (out of all hospices) |       |
|----------------|------------------------|-------|------------------------|---------|---|-------|
|                | FY84                   | FY85  | FY84                   | FY85    | FY84  | FY85  |
| Freestanding   | \$522                  | 591   | \$2,242                | \$4,606 | 0(32)   | 0(63) |
| Hospital-Based | 450                    | 407   | 5,062                  | 6,671   | 0(19)   | 0(39) |
| SNF-Based      | 807                    | 1,995 | 2,821                  | 4,292   | 0(6)  | 0 (5) |
| HHA-Based      | 94                     | 321   | 6,298                  | 3,961   | 0(34)   | 0(63) |

<sup>1</sup>Adjusted for each accounting year for the medical care component of the consumer price index (cap valued at \$7,391 for the period 11/1/85 to 10/1/86).

Source: FY84, 85 HCFA Hospice Benefit Utilization File.

Table 14

**Percent Patient Service Utilization by Hospice Type**  
**Utilization Sample**

|                         | All  |      | Free-Standing |      | Hospital Based |      | SNF-Based |      | HHA-Based |      |
|-------------------------|------|------|---------------|------|----------------|------|-----------|------|-----------|------|
|                         | FY84 | FY85 | FY84          | FY85 | FY84           | FY85 | FY84      | FY85 | FY84      | FY85 |
| Routine Home Care       | 89   | 89   | 96            | 92   | 91             | 84   | 73        | 79   | 81        | 92   |
| Continuous Care         | 14   | 11   | 12            | 12   | 10             | 5    | 2         | 3    | 21        | 16   |
| Inpatient Hospital Care | 1    | 2    | 1             | 1    | 3              | 3    | 2         | 3    | 1         | 2    |
| General Inpatient Care  | 27   | 28   | 16            | 19   | 31             | 43   | 57        | 56   | 32        | 22   |
| Physician Services      | 14   | 13   | 11            | 14   | 21             | 13   | 7         | 11   | 18        | 11   |

Source: FY84, 85 HCFA Hospice Benefit Utilization Files.

physician services. These changing patterns of utilization may have resulted from changing patient mix, from changing practice among existing certified hospices, from increasing disallowance of inpatient or continuous care claims by fiscal intermediaries, or from the entry in FY85 of new certified hospices with different practices regarding provision of home versus inpatient care. Data from three years experience under the Benefit will be used in next year's report to address this issue.

How much does the Hospice Benefit cost in comparison to conventional care?

Hospice Benefit patients incurred lower Medicare reimbursements than conventional care patients in the last month of life, but higher reimbursements from months two to six (counting back from death). On average, Hospice Benefit patients incurred \$717 less in Medicare reimbursements payment than conventional care patients over the last month of life.

Data from Medicare Hospice Benefit and Regular Part A claims are used in this section to compare reimbursements for Benefit enrollees with a sample of Medicare conventional care patients who died in FY85. These comparisons do not prove that the Benefit represents a source of saving to Medicare, because no correction is made for the possibility that payments differences represent effects of patient self-selection or other potential confounding factors. These issues are discussed in Section 6.0, where a preliminary test of the Benefit's cost saving potential is also presented. A full statistical savings analysis will be conducted for the final Evaluation Report in 1988.

Medicare reimbursement patterns over the last seven months (210 days), shown in Table 15, reinforce the NHS conclusion that the largest cost impact of hospice occurs in the last month of life. Conventional care reimbursements grew 136 percent, from \$1532 in month 2 to \$3608 in the last

Table 15

FY85 Hospice Benefit and Conventional Care Patients  
Total Medicare Payment By Month (Last Seven Months)

| MONTH,<br>YEAR                     | 1-7<br>(N=1363) | Hospice: Length of Enrollment (Days) |                  |                   | Conventional<br>Care Patients |                   |
|------------------------------------|-----------------|--------------------------------------|------------------|-------------------|-------------------------------|-------------------|
|                                    |                 | 31-60<br>(N=1228)                    | 61-90<br>(N=537) | 91-120<br>(N=188) | 121-150<br>(N=100)            | 151-180<br>(N=61) |
| Month 1<br>(Last Month<br>of Life) | \$2,955         | \$3,020                              | \$2,716          | \$2,443           | \$2,481                       | \$2,124           |
| Month 2                            | 1,575           | 1,803                                | 2,631            | 2,085             | 1,802                         | 1,819             |
| Month 3                            | 1,071           | 1,098                                | 1,743            | 2,381             | 1,944                         | 1,742             |
| Month 4                            | 927             | 814                                  | 1,123            | 1,747             | 1,921                         | 1,683             |
| Month 5                            | 712             | 729                                  | 845              | 1,217             | 1,959                         | 1,878             |
| Month 6                            | 608             | 637                                  | 679              | 969               | 1,360                         | 1,132             |
| Month 7                            | 526             | 584                                  | 568              | 619               | 995                           | 761               |
| Last Year<br>of Life               | 10,297          | 10,578                               | 12,868           | 13,672            | 14,809                        | 14,061            |
|                                    |                 |                                      |                  |                   | 20,755                        | 18,929            |
|                                    |                 |                                      |                  |                   |                               | 11,256            |
|                                    |                 |                                      |                  |                   |                               | 11,676            |

Source: FY85 Hospice Benefit and Conventional Care Patient Files.

month, but Part A plus Hospice Benefit reimbursements increased by only 52 percent, from \$1903 to \$2891. Lower last-month reimbursements to Hospice Beneficiaries prevailed across all length-of-stay cohorts. The highest last month average reimbursement (\$3044 for patients enrolled 151 to 180 days before death) was 84 percent of the conventional care figure.

Hospice Beneficiaries' reimbursements before the last month were generally higher than conventional care reimbursements. This could be due in part to the additional expenses of hospice, relative to conventional treatment, a difference that is most pronounced at the month of enrollment (due, in part, to the fact that many Beneficiaries enrolled immediately after a hospital discharge). For example, patients enrolled between 61 and 90 days from death cost \$2,381 in the third month, higher than costs in that month of patients enrolled earlier and higher than patients not yet enrolled. Another influence is likely to be length of illness, or length of active intervention. Patients enrolled between 151 and 180 days from death incurred higher expenditures than the average conventional care patient, partly because (based on NHS findings) these hospice patients were diagnosed as terminal earlier than the average conventional care patient. Unfortunately, the Benefit Evaluation data cannot reveal how much of the difference in payments is attributable to different lengths of illness, because date of cancer diagnosis is not available from Medicare claims and enrollment records.

How do components of Medicare reimbursements for hospice and conventional care differ?

Hospice beneficiaries incurred reimbursements in FY85 that were lower than Medicare cancer patients who were treated with conventional care in the last month of life and higher than (or nearly equal to) conventional care in earlier months because:

- Total inpatient reimbursements for Benefit enrollees were generally somewhat higher than conventional care up to the last month; in the last month, conventional care hospital reimbursements accelerated to twice the level of hospice reimbursements.
- Total home care reimbursements were higher for Benefit enrollees in every month, both before and during enrollment, with strong evidence that home services substituted for both regular Part A and Benefit-reimbursed hospital services in the last month of life.

Table 16 shows that most of the difference between hospice (\$8,581) and conventional care inpatient reimbursements (\$11,038) over the last year of life came in the last month. Hospice Benefit payments (for general inpatient and respite care) increased but remained small relative to conventional care payments, and Part A payments fell as enrollees elected the Benefit and reduced (but did not eliminate entirely) their utilization of Part A hospital services.<sup>1</sup>

As expected, Benefit patients used home services more extensively than conventional care patients, by roughly ten to one in the last month of life (Table 17). Somewhat less expected was the relatively high Part A expenditure for home health incurred by Benefit patients throughout the last seven months of life. Although the two groups were similar in home care use at seven months, hospice patients' home care reimbursements grew at roughly ten times the rate of conventional care patients' reimbursements between the seventh and the last month. Without carefully-controlled statistical tests (to be conducted for next year's report), it is impossible to tell how much the Hospice Benefit encouraged substitution of home for inpatient care in this patient population. Clearly, many hospice patients used more Part A-

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<sup>1</sup>Part A payments for "enrollees" include services not covered by the Benefit and services incurred by those who leave and return to the program or who are discharged alive. Most of Part A payments in each month cover beneficiaries' hospital services before enrollment in the Benefit.

Table 16

FY85 Medicare Reimbursements for Inpatient Services:  
Hospice Benefit and Conventional Care Patients

| Month             | Hospice<br>(N = 4,710) |         |         | Conventional Care<br>(N = 7,467) |
|-------------------|------------------------|---------|---------|----------------------------------|
|                   | Hospice<br>Benefit     | Part A  | Total   | Total<br>Part A                  |
| Last Month        | \$575                  | \$1,349 | \$1,924 | \$3,469                          |
| Month 2           | 95                     | \$1,425 | \$1,520 | \$1,435                          |
| Month 3           | 29                     | \$1,097 | \$1,126 | \$1,006                          |
| Month 4           | 10                     | 873     | 883     | 820                              |
| Month 5           | 3                      | 730     | 733     | 720                              |
| Month 6           | 3                      | 622     | 625     | 629                              |
| Month 7           | 2                      | 540     | 542     | 584                              |
| Last Year of Life | 729                    | 8,581   | \$9,310 | 11,038                           |

Source: FY85 Hospice Benefit and Conventional Care Files

Table 17

**FY85 Medicare Reimbursement for Home Care Services:**  
**Hospice Benefit and Conventional Care Patients**

| Month             | Hospice<br>(N = 4,710) |        |       | Conventional Care<br>(N = 7,467) |
|-------------------|------------------------|--------|-------|----------------------------------|
|                   | Hospice<br>Benefit     | Part A | Total | Total<br>Part A                  |
| Last Month        | \$859                  | \$78   | \$937 | \$85                             |
| Month 2           | 267                    | 99     | 366   | 68                               |
| Month 3           | 92                     | 80     | 172   | 53                               |
| Month 4           | 41                     | 61     | 102   | 46                               |
| Month 5           | 24                     | 46     | 70    | 38                               |
| Month 6           | 15                     | 37     | 52    | 34                               |
| Month 7           | 9                      | 29     | 38    | 30                               |
| Last Year of Life | 1,324                  | 538    | 1,862 | 466                              |

Source: FY85 Hospice Benefit and Conventional Care Patient Files

reimbursed home care than conventional care patients. This suggests that some Benefit-reimbursed home services may have been added on to already high levels of home care utilization.

When aggregated to the provider level, utilization data in Table 18 show that most Medicare-certified hospices have easily complied with the 20 percent limit on inpatient days required by the Benefit legislation. The average inpatient percentage grew slightly between FY84 and 85, from 9 to 11 percent. As Table 19 shows, SNF-based hospices, with 3 of 6 and 2 of 5 providers above the limit in each year, were least successful in restricting inpatient utilization. Freestanding and HHA-based hospices were most successful.

#### Other Hospice Benefit Expenses: Physician Services

Charges for physician services dropped from two to one percent of total Benefit charges per patient between FY84 and 85 (see Table 12). These figures tell only part of the story, however. Enrollees' attending physicians may bill for services through Medicare Part B. Part B claims of Hospice Beneficiaries have not been fully analyzed in this Evaluation, but an assessment of data received so far shows that few Part B claims have been filed by Beneficiaries while enrolled in hospice. (Part B data for hospice and conventional care patients will be analyzed in the final Evaluation Report). This suggests either that physicians do not bill for some services provided to Beneficiaries or that physicians' independent contributions to the direct care of Medicare Hospice Beneficiaries has so far been minimal. However, physicians' contributions in administrative roles, particularly through planning and coordinating activities of the interdisciplinary team, are recognized in the standards for participating Medicare-certified hospice.

Table 18

**FY84, 85 Medicare-Certified Hospice Providers Conformance  
to Twenty Percent Inpatient Limit**

| Hospice Type   | Minimum % |      | Maximum % |      | Number 20 Percent or Greater |       |
|----------------|-----------|------|-----------|------|------------------------------|-------|
|                | FY84      | FY85 | FY84      | FY85 | FY84                         | FY85  |
| Freestanding   | 0.0       | 0.0  | 20.0      | 60.8 | 0(32)                        | 5(63) |
| Hospital-Based | 0.0       | 0.0  | 82.5      | 70.2 | 4(19)                        | 8(39) |
| SNF-Based      | 0.0       | 0.0  | 38.0      | 25.3 | 3(6)                         | 2 (5) |
| HHA-Based      | 0.0       | 0.0  | 57.9      | 39.8 | 5(34)                        | 4(63) |

Source: FY84, 85 HCFA Hospice Benefit Utilization Files

### Conclusion

Medicare reimbursements for on Hospice Benefit patients have grown faster than the rate of medical price inflation between FY84 and 85. However, reimbursements per average Hospice Beneficiary were lower than average conventional care reimbursements in FY85. Hospice Beneficiaries, most of whom enrolled during the last month of life, achieved a comparative cost advantage by incurring inpatient expenditures in this period lower than those incurred by non-hospice patients.

Did these reimbursement differences represent "savings" to the Medicare program? To make this assertion, one must show evidence that reimbursements incurred for hospice beneficiaries in hospice were lower than they would have been for these individuals in conventional care (or, conversely, that conventional care patients' reimbursements were higher than they would have been in the Benefit).

Has the Medicare hospice Benefit been cost effective? Regardless of whether or not the Benefit produced cost savings, an assessment of other outcomes, including patient and family quality of life, is needed to weight the relative effectiveness of hospice care.

The issue of cost savings and cost effectiveness is addressed in Section 6.0. In addition, early evidence on the fairness of Medicare payments under the Benefit will be discussed. A full evaluation of both questions must wait until next year's report, which will include patient and provider data for the period after the Benefit became a permanent Medicare entitlement, with legislatively mandated \$10 increases in the Benefit per diem payment rates.

6.0        THE MEDICARE HOSPICE BENEFIT: IS IT COST EFFECTIVE AND EQUITABLE?

6.1        Overview

The Medicare Hospice Benefit is cost effective for Medicare, if it reduces Federal expenditures below what they would have been had Beneficiaries been placed in other settings without compromising desirable outcomes, such as pain and symptom control, and other dimensions of the quality of life. Cost data reviewed in Section 5.0 show that Beneficiary reimbursements were lower than reimbursements for a "comparison group" of conventional care patients. Research conducted by the NHS and by Kane et al. have shown little measurable difference between hospice and conventional care in quality of life outcomes. Why cannot we simply conclude from these findings that the Hospice Benefit is cost-effective?

Even if we accept quality of life findings from previous research as valid and applicable to patients under the Benefit, we still cannot conclude that the Benefit is cost effective for the Medicare program without addressing the issue of patient selection bias:

Are all estimated differences between patients' hospice and nonhospice expenditures flawed, because they reflect characteristics of the patients that selected one or the other settings, rather than the impact of hospice on utilization?<sup>1</sup>

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<sup>1</sup>Provider selection bias poses another threat to long run projections of cost savings and cost effectiveness. If, as we suggested in Section 3.0, hospices that first gained certification were different from the average U.S. hospice, then any hospice-nonhospice cost difference could be only temporary. In this scenario, less efficient, high cost hospices that enter the Medicare program later could create continuing pressures to increase the Medicare Benefit rates, narrowing or eliminating any "savings" that were generated just after Benefit implementation. Of course, the opposite pattern may have prevailed: inefficient hospices, in search of revenue sources, may have been the first to seek certification. The effect of a change in provider composition on net costs of the Benefit program will be studied and reported in the 1988 final Evaluation Report.

There are two methods that have been used in previous studies to control for patient selection effects:

- Statistical techniques or random assignment are employed, to produce "comparable" patients treated in hospice and nonhospice settings. Statistical methods were used by Greer and his colleagues in the NHS. Random assignment was used by Kane and his colleagues.
- Hospice utilization and expenditure patterns are superimposed on a sample of non-hospice patients, and non-hospice expenditures saved, compared to hospice expenditure that would be added, are computed. HCFA's Office of the Actuary (HCFA/OACT) used this method to estimate the financial implications for the Medicare Trust Fund of implementing the Benefit.

This report applies the HCFA/OACT methodology to FY85 data, in a preliminary examination of the Benefits' implications for Medicare cost savings. However, because the first two years of the Benefit were characterized by legislative and regulatory changes in payments and conditions, as well as adjustment problems of the newly-certified hospices, a longer period, over which most participating hospices have "adjusted" their behavior to the Benefit, will provide more reliable expenditure data. Therefore this Evaluation will employ both methodologies to study hospice cost savings, using patient level data for three full years (FY84-FY86), the findings of which will be presented in the 1988 final Evaluation Report.

The principal finding from this preliminary analysis is that, depending upon certain assumptions, the Hospice Benefit either saved or cost slightly more than conventional care for FY85 enrollees with stays of 30 days or less. Cost differences varied across hospice types; freestanding and HHA-based programs showed savings, but hospital- and SNF-based programs showed savings under one set of assumptions and excess costs under another. Since the average hospice enrollee stayed 32.1 days, and over half of all enrollees stayed under one month in the program, the preliminary conclusion is that, at

worst, the Hospice Benefit has produced a small increase in Medicare reimbursements for patient care, and at best, it has saved reimbursements.

Even if the Benefit should prove to be cost effective in the short run, the payment methodology and conditions of participation may promote inequities that will discourage providers and beneficiaries from participating to the extent anticipated by Congress. Therefore, this section also examines issues of payment equity, focusing on adequacy of the per diem rates and on treatment in the Benefit of specific services: outpatient drugs, dietary and nutritional counseling and bereavement counseling. A preliminary conclusion of the analysis is that, under either FY84 rates or rates set in COBRA that apply to claims submitted after April 1, 1986, participating hospices are, for the most part, paid at or below their costs. However, there is no evidence from early cost report data that support a change in payment methods to recognize outpatient drugs, dietary and bereavement counseling. Whether or not the current payment methodology discourages potential entrants into the Medicare program cannot be answered without data from noncertified hospices; these data will be analyzed and reported next year.

This section begins by reviewing prior research on hospice savings, reviews criticism of this research and describes methodologies designed to study the issue in this Evaluation. Results of the preliminary savings test using FY85 data are presented. Findings from previous research regarding hospice/non-hospice differences in quality of life outcomes are reviewed (no original research on these issues is included in the scope of work for the Benefit Evaluation). Finally, issues of payment equity and fairness are reviewed, using Medicare Hospice provider cost report data from the first year of the Benefit.

How much does hospice save over conventional care?Evidence from Prior Research

The size of hospice savings has been estimated to range from zero (Kane et al., 1984) to over 800 percent (Morgan et al., 1982), measured as a percentage of conventional care costs. The NHS found that conventional care costs exceeded hospice costs by over 100 percent in the last month of life; savings over the last year were \$585 in patients for bedded hospices and \$2221 for in non-bedded hospices.

Estimated hospice savings are largest during the last two months of life. Most studies have found the average enrollment period to be between one and two months, with half of all hospice expenditure incurred during the period of maximum relative cost advantage. This pattern of savings occurs because conventional treatment expenditure accelerates rapidly during the last two months, driven mainly by increased hospitalization rates and escalating ancillary costs; hospice costs grow but much less rapidly, and hospital costs for many hospice patients actually decline in the last month. (Brooks and Smyth-Staruch (1984); Mor and Kidder (1985)) In contrast, for long stay hospice patients, savings may be replaced by costs, in excess of the average conventional care patient, particularly in the earlier months when hospice enrollees are receiving more home care services.

Organizational structure appeared to affect saving potential in earlier research. In studies completed before implementation of the Hospice Benefit, non-bedded hospices were shown to have larger savings than bedded hospices. Non-bedded hospices achieved savings by maintaining their patients

at home for more days in the last weeks of life than either bedded hospices or conventional care providers.

However, patient characteristics do not seem to affect savings, because potential influences such as diagnosis, age, sex and living arrangement all tend to raise or lower costs in similar ways in hospice and conventional care. Of course factors such as cancer type and living arrangement may influence choice of hospice, because it may be more efficient to care for patients in hospice if home support is available, and because certain cancers, such as colon cancer, may be more easily treated at home than others, such as leukemia. (Brooks and Smyth-Staruch, 1984).

This discussion shows why one has to be careful to define conditions under which hospice has been shown to save costs relative to nonhospice care:

- Third party payers that offer generous hospitalization benefits such as Medicare have apparently saved in the past, in part because savings have been achieved through reduced rates of hospitalization, and substitution of home for inpatient care;
- Hospice programs that place patients at home have saved more than hospices that do not; for the most part, the former have been hospices that have no inpatient capacity, and the latter have been hospital-based or free-standing, bedded hospices. (These distinctions have not been important for Medicare certified hospices, however.)

#### Early Estimates of Cost Savings Under the Benefit

In the course of Federal hospice policy development, two radically different views of the Benefit's future impact on the Medicare Trust Fund emerged. On the one hand, the Congressional Budget Office (CBO) predicted net Medicare savings for the program, after two years (1983 and 1984) of net start-up costs. On the other hand, HCFA/OACT predicted net Medicare costs associated with the Benefit, from the beginning of the program through 1987. Both parties updated their analyses in 1985. In its revision, the CBO

extended its predictions through 1990, and defended the argument that hospice would continue to generate savings. HCFA/OACT reestimated net costs, using complete data from the National Hospice Study, and reaffirmed its conclusion that hospice would generate net costs. (Table 19) HCFA/OACT revised its estimate of net costs, on which the 1982 projection was based, from \$0.64 in conventional care costs saved for every additional dollar spent on hospice to \$0.52 using more recent data. (OACT Actuarial Note 85-02, October 29, 1985).

The reasons why these predictions are so different are complex. Each prediction required assumptions about how many beneficiaries would be affected, how long they would be in hospice, how much of each type of service would be used in hospice and, during a comparable period, in conventional care. Most of the differences between the HCFA/OACT and CBO models were due to the cumulative effects of slightly different judgments about how to use the available data and how to cope with missing information. However, two major areas of difference deserve some attention.

First, each group approached the question of savings in hospital costs differently. In its original projection, the CBO estimated that Medicare hospital payments in the last 45 days of life averaged \$5,700 in 1983; this represents about 18 hospital days, at average Medicare per diem reimbursement rates for that year. CBO subtracted 2 days from this figure, to allow for non-hospice hospitalization of hospice beneficiaries at the end of life, yielding a net saving in non-hospice hospital days of about 16 days. (CBO, unpublished). CBO made no assumption about how many inpatient days would be added during the hospice enrollment period. NHS data, netting added hospice inpatient days against saved hospital days, yielded a net saving of about 11 days.

Table 19

**Medicare Hospice Benefit Costs/Savings Projections: HCFA and CBO**  
(millions of dollars)

Note: Positive values represent net costs; negative values represent net savings.

| Year | <u>HCFA</u> | <u>CBO</u> |         |
|------|-------------|------------|---------|
|      |             | Original   | Revised |
| 1983 | \$45        | \$10       | -       |
| 1984 | 60          | 3          | -       |
| 1985 | 80          | -13        | -       |
| 1986 | 115         | -38        | -       |
| 1987 | 160         | -71        | -4      |
| 1988 |             |            | -5      |
| 1989 |             |            | -7      |
| 1990 |             |            | -1      |

Sources: HCFA. Memo to the Administrator (April 1982)  
CBO. Cost Estimate (June, 1982)  
CBO. Revised Cost Estimate (June, 1985):  
Three Year Extension of the Benefit

HCFA/OACT's initial estimates were based on an assumption about admissions saved rather than days saved, the assumption in the first CBO estimate.<sup>1</sup> Data from the Medicare History File (1979 through 1981) were used to estimate charges per hospitalization and the number of hospitalizations experienced after cancer was diagnosed. HCFA/OACT noted that nearly 37 percent of patients hospitalized at the time of diagnosis were never readmitted to a hospital for the same cancer diagnosis.<sup>2</sup> Thus for some groups the number of post-diagnosis admissions assumed to be saved by hospice enrollment was relatively small; for example, among the 1,270 sample patients diagnosed within 3 months of death, HCFA/OACT argued that only 485 admissions would be saved by hospice. The additional cost of 34,875 hospice days for this group, estimated to be \$2,628,058, exceeded predicted hospital savings by \$1,112,152 (HCFA/OACT, unpublished).

6.3      Have estimated Hospice savings been based on the wrong kinds of patient comparisons?

Critics have charged that the wrong kinds of conventional care patients have been used as control groups in hospice savings analyses. The ideal comparison to show that hospice saves money would match patients identical in every respect except for the fact that one entered hospice and one did not. Of course, this ideal can only be approached in practice rather than fully realized. However, the critics contend that previous research has used patient selection methods that actually reduce comparability. In particular:

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<sup>1</sup>CBO's revised savings estimates were also based on hospice effects on hospital admissions.

<sup>2</sup>Given the near impossibility of deciding from coded diagnoses whether or not a hospital admission as or was not related to patients' terminal cancer conditions, exclusion of all "unrelated" admissions was probably not justified.

- Conventional care patients have been sampled from hospital records and third party billing systems. Thus, conventional care samples tend to be dominated by patients who use health care services; to the extent that hospital use is the point at which conventional care patients are identified, these might be especially heavy users of services.
- Patients missed by this sampling procedure include terminally-ill patients in the conventional care population who might be attracted to use the Hospice Benefit. Among these are individuals who die at home, and individuals who have adopted a low intensity "hospice-like" regime of care without the extra services that hospice provides.
- Hospice patients are more likely to come from the population of less intensive users of care.
- Therefore, studies that predict savings are comparing patients who are predisposed toward low levels of utilization (hospice patients) with that part of the conventional care population predisposed to use above average levels of care (patients identified through medical records).

If these criticisms are correct, an analysis based on these data would be misleading for two reasons:

- From a technical point of view, comparing patients that are systematically different means that it will be impossible to say what effects hospice had on relative costs, as opposed to effects associated with patients being predisposed to a high or low level of utilization. Careful sampling and statistical analysis can minimize this problem.
- From a policy standpoint, it becomes difficult to predict what might happen to program costs and savings if patient types not sampled are later attracted to the Benefit; for example, if more low-intensity, conventional care patients elect hospice care over time, their costs in hospice may be higher than they would have been in conventional care. In addition, if the percentage of non-hospice patients who die at home or choose palliative over aggressive care grows over time, sampling from hospital records will widen the gap between patients in hospice care and patients chosen to represent the non-hospice population. This is because an increasing proportion of the most aggressively (and expensively) treated non-hospice patients will be captured from hospital records. Estimates of hospice saving will be subject to increasing bias over time.

How serious are these criticisms?

- There is a population of "low intensity" non-hospice patients. Of the 7,467 FY85 conventional care patients sampled for the Hospice Benefit Evaluation, 43 percent died at home or in another non-hospital setting. Part A payments to this group were \$1,557 per patient in the last month of life, compared to \$3,610 for the average conventional care patient.
- The percentage of all patients (hospice and non-hospice) dying at home appears to be increasing. HCFA/OR analysts, using NCHS mortality data, have shown that, over time, fewer patients are dying in the hospital. In 1980, about 27 percent of cancer decedents died out of the hospital (see Table 20). By 1984, this figure had grown to 35 percent. Death at home, the least costly setting for Medicare, showed the largest percentage increase (5.8 percent) between 1980 and 1984.
- There is little evidence that the charges for hospital care furnished to dying Medicare patients has declined relative to care for patients who did not die at discharge. Data from the Medicare 20 Percent File show that the relative costs of treating terminally ill patients in hospitals has not changed dramatically in recent years; findings reported here confirm earlier results reported by Scitovsky (1984). If hospital stays among the terminally ill were to reflect a tendency to adopt low-intensity hospice-like approaches to treatment, one might expect to see that the ratio of hospital costs between cancer patients discharged alive and dead would begin to rise. In 1980, the average charges for a live discharge were about two-thirds of the charges for a dead discharge. This ratio has risen slightly (Table 21) but the change is too small to establish a trend. In addition, although ratios for specific ancillary services have risen and fallen between 1980 and 1982, there are no obvious trends.

Clearly, there are utilization patterns of widely divergent intensity among dying patients, based solely on the evidence regarding place of death. Researchers need to be careful to minimize the danger of inflated estimates of hospice savings, due to potential favorable patient selection into hospice programs.

Table 20

Cancer Mortality, Percentage by Site of Death

1980-1984

Cause of Death: All Malignances

| (ICD9-CM 140-208)<br>By Age and<br>Site of Death | 1980  | 1981  | 1982  | 1983  | 1984  | 1980-1984<br>Percent<br>Difference |
|--|-------|-------|-------|-------|-------|------------------------------------|
| <b>65 - 74 years of age</b>                      |       |       |       |       |       |                                    |
| Hospital   | 74.2% | 74.1% | 73.2% | 71.6% | 67.3% | -6.9%                              |
| Other Institutions                               | 9.3   | 8.8   | 8.8   | 9.1   | 10.6  | +1.3                               |
| Dead on Arrival                                  | 2.8   | 2.6   | 2.6   | 2.4   | 2.4   | -0.4                               |
| Other Places (home)                              | 13.7  | 14.6  | 15.5  | 17.0  | 19.7  | +6.0                               |
| <b>75-84 years of age</b>                        |       |       |       |       |       |                                    |
| Hospital   | 66.5% | 66.0% | 65.1% | 63.3% | 58.5% | -8.0%                              |
| Other Institutions                               | 17.4  | 17.3  | 17.1  | 17.6  | 19.7  | +2.3                               |
| Dead on Arrival                                  | 2.6   | 2.3   | 2.3   | 2.2   | 2.2   | -0.4                               |
| Other Places (home)                              | 13.4  | 14.4  | 15.6  | 16.9  | 19.5  | +6.1                               |
| <b>85+ years of age</b>                          |       |       |       |       |       |                                    |
| Hospital   | 54.9% | 54.9% | 53.6% | 51.4% | 46.9% | -8.0%                              |
| Other Institutions                               | 29.9  | 30.0  | 30.6  | 31.1  | 33.8  | +3.9                               |
| Dead on Arrival                                  | 2.2   | 2.1   | 1.9   | 2.0   | 2.0   | -0.2                               |
| Other Places (home)                              | 12.9  | 13.0  | 13.9  | 15.5  | 17.2  | +4.3                               |
| <b>All Ages</b>                                  |       |       |       |       |       |                                    |
| Hospital   | 72.7% | 72.1% | 71.0% | 69.2% | 65.4% | -7.3%                              |
| Other Institutions                               | 10.9  | 10.8  | 11.0  | 11.4  | 12.9  | +2.0                               |
| Dead on Arrival                                  | 2.8   | 2.6   | 2.5   | 2.4   | 2.4   | -0.4                               |
| Other Places (home)                              | 13.5  | 14.4  | 15.4  | 17.0  | 19.3  | +5.8                               |

Source: NCHS, Table 1-28. Deaths from 34 Selected Causes by Place of Death, Status of Decedent When Death Occurred in Hospital or Medical Center and Age: Total of 40 Reporting Areas, 1980, 1981, 1982, 1983, 1984.

Table 21

Medicare Charges per Cancer Admission:  
Ratio of Live to Dead Discharges  
(1980 - 1982)

| Service Category                         | 1980 | 1981 | 1982 |
|--|------|------|------|
| All services<br>(routine plus ancillary) | .67  | .68  | .69  |
| All ancillary services                   | .65  | .67  | .66  |
| Intensive care/coronary care             | .53  | .55  | .53  |
| Operating room                           | .83  | .86  | .83  |
| Pharmacy                                 | .48  | .49  | .46  |
| Radiology                                | .84  | .85  | .89  |
| Supply                                   | .59  | .61  | .58  |
| Inhalation therapy                       | .56  | .57  | .80  |
| Laboratory                               | .60  | .61  | .61  |
| Anesthesiology                           | .83  | .81  | .82  |

Source: Medicare 20 Percent File (MEDPAR)

#### The Hospice Benefit Evaluation Methodology

The Medicare Hospice Benefit Evaluation is addressing the patient selection issue through the use of:

- proportional random sampling of Medicare claims from a population of non-hospice Medicare patients who died in each year, across counties with Medicare-certified hospice(s) (45 percent) with only noncertified hospice(s) (43 percent) and with no hospices. The relevant populations were defined as all patients with a date of death and at least one Medicare claim recording a diagnosis of cancer or other life-threatening condition within the two year period before death. This method increases the likelihood that patients similar to Hospice Benefit enrollees will be selected, in view of the fact that only 7 percent of FY85 Benefit enrollees had no Part A-reimbursed utilization in the two years preceding death. It also permits comparisons between Hospice Benefit patients and patients in counties not served by hospice, so that the favorable/adverse self-selection that could occur between the settings in a hospice-served county can be avoided.
- analytical methods to control for remaining differences in patient and area characteristics that might account for part of any hospice/non-hospice cost difference.

Two analytical models will be employed:

- An actuarial approach, based on HCFA/OACT's methodology for computing net Benefit costs. The conventional care patient sample is used in this approach to answer the question: if these patients were treated as the average Hospice Beneficiary was treated, what would be the net effect on Medicare reimbursement?
- A statistical approach, based on the linear regression methodology used in the NHS. Hospice Benefit and conventional care data are used to estimate a model that controls for patient and area influences on hospice/conventional care cost differences. The question addressed resembles HCFA/OACT's question: what is the difference in Medicare reimbursement for "comparable" patients treated in hospice or conventional care? However, this offers another test of the savings question that will either confirm or call into question results of the actuarial approach.

For this year's report, a preliminary actuarial analysis of savings was conducted using FY85 data; both models will be employed, using all three

years' study data, in next year's report. The conventional care sample for this analysis included 3,220 cancer patients who died in FY85. Of these, 2,964 had data sufficiently complete for inclusion in the cost comparisons.

The following steps led up to our estimate:

- "Windows" of time, counting from death back (5 days or less, 10 days or less, 15 through 90 days or less) were constructed for each conventional care patient with complete claims and DRG information. Within each window, hospital episodes were counted, measured (in days) and matched with their associated charges and Medicare reimbursement (at the appropriate national DRG rate). Two kinds of episode counts were made:
  - Type A: only Part A-reimbursed hospital episodes beginning and ending within the window were counted.
  - Type B: Part A-reimbursed hospital episodes ending within the window, including Type A plus episodes overlapping the windows' boundaries were counted.
- Each window was divided into hospital days and non-hospital days.
- Total Medicare hospital reimbursements were assigned to each window. These included mainly DRG payments plus an "average" add-on for pass through costs (mainly capital and medical education). Based on conversations with HCFA staff, this add-on was set at 10 percent of total DRG payments.
- Non-hospital days were assumed to be paid at the average non-hospital Part A reimbursement per day (for skilled nursing and home health care services) estimated from data for the FY85 conventional care sample.
- Total Medicare Part A payments per patient window were computed as the sum of hospital and non-hospital payments. A percentage of this total (10 percent) was added to account for Part B payments.<sup>1</sup> Average conventional care per diem reimbursements were computed for each window by dividing total reimbursements by the number of days in the window.

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<sup>1</sup>The exact percentage is unknown, because Part B data for conventional care patients have not been acquired yet for this Evaluation. However, the 10 percent estimate roughly conforms to findings regarding terminal cancer patients' expenditures on physician, outpatient drugs and supplies in the National Hospice Study. (Greer, et al, op cit.)

- Average per diem Medicare reimbursements (Benefit plus Regular Part A) paid to Hospice Beneficiaries were computed for length-of-enrollment categories that matched conventional care windows (stays of five days or less, 10 days or less, etc.)

An estimate of the dollar difference between the hospice and conventional care was obtained by subtracting what would have been reimbursed for a hospice patient, had enrollment occurred at five days before death, 10 days, etc., from what would be saved in conventional care reimbursement. The assumption regarding how many hospital episodes to count as saved is critical in this comparison. If one assumes that hospice patients would not enroll during an inpatient episode, and would therefore not "save" the hospital episode that overlaps the hypothetical enrollment date, (the Type A assumption) then fewer hospital episodes are saved by hospice, relative to a Type B assumption, and savings are smaller. Some evidence suggests, however, that some hospice patients make a decision to enter hospice and begin to modify their behavior (by relying more on home care, for example) before enrolling. In one case study of nine hospice patients and twelve primary caregivers, researchers reported that "...(in) nearly every case, the decision to remain at home was made before the decision to use hospice." (Leloudis and Pole, 1985) If this pattern prevails, the Type B assumption, which counts the overlapping hospital stay as a "saved" episode, is the correct one; this approach yields larger savings than the Type A approach.

For example, hospice reimbursements over a 20-day enrollment period were estimated to be \$101 per day (see Table 22); conventional care reimbursements for the same period, under a Type A assumption, were \$98 per day. Hospice "cost" Medicare \$3 a day more than conventional care, for patients enrolled in this interval. However, using the Type B assumption, conventional care costs saved were \$169 per day during the 20-day window so

Table 22

Net Hospice Savings Per Day<sup>1</sup> By Assumed Length of Stay

| Windows/<br>Length<br>of Stay<br>Cohorts | N <sup>2</sup> | Inpatient Episode Assumption <sup>3</sup> |   |                      |                                     |   |                      |
|--|----------------|---|---|----------------------|-------------------------------------|---|----------------------|
|  |                | Type A                                    |   |                      | Type B                              |   |                      |
|  |                | Hospice<br>Reimbursement<br>Per Day       | Conventional Care<br>Reimbursement<br>Per Day | \$Savings<br>\$Costs | Hospice<br>Reimbursement<br>Per Day | Conventional Care<br>Reimbursement<br>Per Day | \$Savings<br>\$Costs |
| 5 days or less                           | 2,964          | \$123                                     |   | 1.00                 | \$123                               |   | 4.24                 |
| 10 days or less                          | 2,830          | 116                                       |   | 0.99                 | 116                                 |   | 2.48                 |
| 15 days or less                          | 2,700          | 108                                       |   | 0.98                 | 108                                 |   | 1.94                 |
| 20 days or less                          | 2,541          | 101                                       |   | 0.97                 | 101                                 |   | 1.67                 |
| 25 days or less                          | 2,381          | 97  |   | 0.97                 | 97                                  |   | 1.48                 |
| 30 days or less                          | 2,251          | 94  |   | 0.96                 | 94                                  |   | 1.36                 |
| 45 days or less                          | 1,933          | 85  |   | 0.92                 | 85                                  |   | 1.19                 |
| 60 days or less                          | 1,674          | 78  |   | 0.92                 | 78                                  |   | 1.09                 |
| 90 days or less                          | 1,270          | 68  |   | 0.91                 | 68                                  |   | 1.00                 |

Source: FY 85 Hospice Benefit and Conventional Care Patient Files.

<sup>1</sup>Defined as dollars saved in conventional care reimbursement divided by dollars of hospice reimbursement.

<sup>2</sup>The number of conventional care patients in each cohort declines, because patients with first recorded cancer diagnoses later than particular windows were excluded from them. Thus all cancer patients whose earliest cancer diagnoses occurred 10 days or less from death were excluded from windows 15 through 90 days.

<sup>3</sup>Type A: The only "saved" regular Part A inpatient episodes were those entirely within the specified window/length of stay cohort.

Type B: The "saved" regular Part A inpatient episodes include both those within the interval and those that begin before and end within the interval.

that hospice "saved" Medicare \$68 per day. In terms of dollars saved per dollar spent (conventional care reimbursements divided by hospice reimbursements), a Type A assumption produces a saving of \$0.97 for every dollar paid for hospice care, but Type B saves \$1.67 for every hospice dollar.

Table 22 shows estimates of hospice and conventional care reimbursements by time period, and the implied saving, for the two assumptions regarding hospital episodes. Using HCFA/OACT's assumption, every dollar spent on hospice care for a patient enrolled for 30 days or less subtracted \$0.96 for every Medicare Hospice Benefit dollar spent. Net costs of hospice rose for longer stays. Type B's more generous assumption about saved hospital stays yielded a saving to Medicare of \$1.36 for each hospice dollar spent; hospice reimbursements were \$94 per day, and conventional care reimbursements were \$128. Net savings based on Type B assumptions declined with longer stays; hospice only saved Medicare \$0.98 for every hospice dollar spent, for 90 day stays.

These figures mask large differences in savings ratios among hospice provider models. As Table 23 shows, freestanding and HHA-based programs generally saved, relative to conventional care, for patients enrolled 30 days or less. Freestanding hospice savings were estimated to be from \$1.01 (Type A assumption) to \$1.43; HHA hospices were nearly "neutral" in their impact with a Type A assumption (\$0.99), but saved \$1.40 under a Type B assumption. In contrast, hospital- and SNF-based hospices only saved under the relatively generous Type B assumptions. At worst, reimbursements for patients enrolled 30 or fewer days in a hospital-based hospice were \$9 per day higher than conventional care (a 0.91 savings ratio); the comparable SNF-based figure, reflecting reimbursements for only 222 patients, was \$23 per day.

Table 23

**Net Hospice Savings Per Day<sup>1</sup> By Assumed Length of Stay  
and by Hospice Provider Model**  
(\\$ savings/\\$ costs)

| Windows/<br>Length<br>of Stay<br>Cohorts | Hospice Provider Model |                   |                   |                   |                   |                   |
|--|------------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
|  | Free-standing          |                   | Hospital-Based    |                   | SNF-Based         |                   |
|  | Type A<br>Episode      | Type B<br>Episode | Type A<br>Episode | Type B<br>Episode | Type A<br>Episode | Type B<br>Episode |
| 5 days or less                           | 1.07                   | 4.53              | 0.88              | 3.75              | 0.73              | 3.10              |
| 10 days or less                          | 1.08                   | 2.69              | 0.91              | 2.27              | 0.74              | 1.86              |
| 15 days or less                          | 1.03                   | 2.06              | 0.89              | 1.78              | 0.82              | 1.64              |
| 20 days or less                          | 1.03                   | 1.76              | 0.90              | 1.54              | 0.78              | 1.34              |
| 25 days or less                          | 1.03                   | 1.53              | 0.91              | 1.38              | 0.77              | 1.18              |
| 30 days or less                          | 1.01                   | 1.43              | 0.91              | 1.29              | 0.77              | 1.09              |
| 45 days or less                          | 0.98                   | 1.25              | 0.90              | 1.14              | 0.77              | 0.97              |
| 60 days or less                          | 0.97                   | 1.13              | 0.88              | 1.03              | 0.77              | 0.90              |
| 90 days or less                          | 0.95                   | 1.05              | 0.88              | 0.97              | 0.78              | 0.86              |

Source: FY 85 Hospice Benefit and Conventional Care Patient Files.

<sup>1</sup>Defined as dollars saved in conventional care reimbursement divided by dollars of hospice reimbursement.

<sup>2</sup>Type A: The only "saved" regular Part A inpatient episodes were those entirely within the specified window/length of stay cohort.

Type B: The "saved" regular Part A inpatient episodes include both those within the interval and those that begin before and end within the interval.

This exercise does not answer the question of how much in total the Benefit has saved Medicare or is likely to save in the future. It does add to a considerable body of evidence that hospice is least costly relative to conventional care in the last month of life. At worst, (using the HCFA/OACT approach), hospice in the last month saved \$0.96 to \$1.00 for every hospice dollar spent. At best, the Benefit yielded savings ranging from \$1.36 to \$4.24.

Thus far, the magnitude of estimated total Medicare savings or costs associated with the Benefit has been small relative to total Medicare expenditures. For example, Medicare paid roughly \$10.3 million for the care of 4,710 Hospice Beneficiaries while enrolled in FY85 (See Table 11). Based on an assumed savings ratio of 0.96, these payments would be associated with a \$9.9 million reduction in conventional care reimbursement, a total excess Benefit cost of \$400,000. A Type B savings ratio of 1.36 would generate \$14.0 million in savings, or a net saving to Medicare of \$3.7 million. Both estimates of net reimbursement effects are well below 0.01 percent of the \$60 to \$70 billion reimbursed annually by Medicare for health care over the last three years.

#### 6.5        Are hospices effective at achieving clinical and other goals?

Hospice care may be judged in terms of general goals (are patients satisfied?) or specific objectives (do hospices generally control pain effectively?). Research has shown that, as with most kinds of medical care, most patients are usually satisfied with the care they receive in hospices (Krant and Johnston, 1977; Jones, 1984; Bonham, et al., 1986); comparing hospice and conventional care, patients and their families were generally pleased with the choices they made. In some studies, hospice patients seemed more satisfied than comparable nonhospice patients. However, comparing the capacities of

hospice and conventional care to reach more specific objectives can provide conservative benchmark measures of hospice effectiveness. If hospices should prove to be no better at achieving their own stated goals than conventional care providers, then more of the burden of "justifying" hospice as cost effective is shifted to the cost side. The specific objectives that will be discussed in this section include:

- control of pain and symptoms
- satisfaction of family and patient needs for counseling and therapies;
- ability to meet needs of staff.

This list excludes somewhat abstract concepts often used to describe the value of the hospice experience, such as the "good death," or a sense of religious or spiritual fulfillment (Witzel, 1975; Stoddard, 1978). Even though these may be the essence of hospice for some people, clinicians and others are not likely to agree or accept them as measurable or even legitimate. It also excludes site of death. Dying at home is often mentioned as a hospice goal, and studies show that a large proportion of hospice patients (well over 50 percent) die at home (Mor and Hiris, 1983; Bonham et al., 1986; Burns and Carney, 1985; Holman, 1986; Hadlock, 1985). On those other elements that are often used to define quality of life, there is still (and will continue to be) disagreement on several points:

- How should the components be weighted? Is pain control more or less important than relieving depression?
- How can any change in outcome be evaluated, in relationship to a particular intervention?
- Can hospice really affect the inexorable changes in patients' physical and psychological condition during the last stages of terminal illness? (Morris et al., in press; Mor et al., 1985)

- Can measures of quality of life really be evaluated independently without knowing the complex set of perceptions and attitudes of those who report them as well as the time (relative to death) and the place (at home or in the hospital) that reports are gathered?

As the discussion that follows will show, it is clear that drawing conclusions about quality outcomes must be done with care.

Does hospice provide effective control of pain, symptoms and other physical conditions that help determine quality of life?

Some studies report that hospices are more effective at controlling chronic pain than conventional care providers; others that do not find any significant difference between hospice and conventional care do note differences between home- and inpatient-oriented hospice care.

Studies that suggest greater hospice effectiveness have tended to rely on proxy measures. Patients at advanced stages in their diseases who were unable to respond were perceived by family members to be experiencing considerable discomfort. Perceptions that hospice was particularly effective at controlling this high rate of pain came also from primary care persons (Barzelai, 1981; Naylor, 1983). Several studies conclude that hospice care has no demonstrably superior capability to limit or prevent pain. (McCusker, 1984; Zimmer et al., 1984; Parkes, 1979; Kane, Bernstein et al., 1985) Sherwood, Morris and Archibald, (1986) note that specific interventions, such as diagnostic x-rays at intake and provision of intravenous services in home settings were more closely associated with favorable pain outcomes among NHS patients than organizational characteristics of hospices.

Other symptoms of terminal illness, such as shortness of breath, nausea, vomiting and cognitive problems have been reported to be present at various levels among patients, depending on diagnosis and the setting of care. As with pain control, the findings on hospice effectiveness in dealing with these symptoms are mixed. Once again, hospital-based hospice care

appears to be marginally more effective than home-oriented care (Greer, Mor, Morris et al., in press; Naylor, 1983). However, taken as a whole, hospice does not appear to have a clear advantage over conventional care (Kane et al., 1984; Kane, Bernstein et al., 1985).

Some researchers have attempted to compare hospice and conventional care using measures that combine pain and symptom control outcomes, or that use self-reported indicators of "well-being." When overall measures are defined purely in terms of physical function, the hospice effect becomes virtually impossible to detect (Greer, Mor, Morris et al., in press; Linn et al., 1982). Deterioration follows a pattern that is predictable, with over half of terminally ill patients being bedridden within the last few weeks of life, regardless of the setting of care (Morris, Suizza et al., in press). Psychosocial measures of well-being show improvements among patients who received counseling. However, it is apparently not simply exposure to hospice that achieves this outcome; rather it is counseling focused toward the patients need, whether in hospice or a conventional setting, that yields improvements (Spiegel et al., 1981; Linn, Linn and Harris, 1982).

Do hospices meet the psychosocial needs of patients and their families effectively?

During the advanced stages of terminal illness, patients may experience feelings of anxiety and depression associated with declining functional capacity. Families and others providing care may reflect these moods, and experience a sense of hopelessness and guilt that may not be fully resolved until months after a patient's death. Hospice advocates argue that the hospice philosophy of caring for the "whole person/family unit" rather than the disease creates a beneficial psychosocial response. However, there are no structured protocols that define a hospice approach either to addressing

psychosocial problems before the patient's death or to providing appropriate levels of bereavement support after death.

There is no conclusive evidence that hospices deal with family guilt and anxiety before the patient dies more effectively than conventional care. Families in hospice programs, particularly those organized around home health agencies, felt more involved in care of the patient than families of conventional care patients (Kane, Klein et al., 1985); this finding was expected in view of the high levels of informal care provided at home for hospice patients. However, greater involvement does not seem to have relieved families of the psychological burdens of facing the death of a close relative (Greer, Mor, Morris et al., in press).

More light has been shed on families' reactions after a patient dies, but again the evidence both on the symptoms of bereavement distress and the relative effectiveness of alternative approaches to bereavement support is mixed. The prevalence of distress is similar among hospice and conventional care families; there is evidence, however, that the type of hospice may be related to primary care persons' reactions. In the HCFA demonstration, primary care persons of home care hospice patients were found to be more depressed and anxious during bereavement than primary care persons of patients in bedded hospice programs (Mor, McHorney and Sherwood, unpublished, 1985). Other studies of palliative care focussing on nonhospice populations do not confirm this result. For the most part, they show that families of patients treated largely at home recover from their experience more rapidly than families of patients who died in a hospital (Mulhern et al., 1983). The reason for this discrepancy is unclear; it is possible that the greater day-to-day involvement of a primary care person in a hospice patient's care at home

(relative both to family of a hospitalized patient or a patient in "conventional" home care) creates a high level of stress leading to depression and burnout.

Does hospice provide effective support for staff members?

The hospice philosophy stresses the importance of commitment and understanding from all staff who deal with patients and their families. Burnout, job dissatisfaction and rapid turnover are responses to stress that may jeopardize the intangible caring quality that many believe to be the essence of hospice. Hospice workers would appear to be particularly vulnerable to burnout under stress. However, there is evidence that contact with terminally ill patients and their families does not itself produce burnout (Vachon, 1986). The idealism of the hospice movement may create expectations, regarding the staff members' own role and responses of patients and their families, that cannot be fulfilled (Koff, 1980; Zimmerman, 1981).

Studies of factors associated with low burnout rates are also not encouraging for certain hospices; these factors include developing a sense of professionalism and establishing clear definitions of roles (Chiriboga et al., 1983; Mor and Laliberte, 1984). However, most hospices appear to be better able to cope with problems of burnout and dissatisfaction than other health care providers. Correlates of success other than professionalism contribute to this outcome. Management "style" in most hospices is relatively open and supportive (Vachon, 1979). Regular meetings of the hospice interdisciplinary team serve a dual purpose of coordinating care and providing a sense of purpose and support (Koff, 1980; Zimmerman, 1981). Nurses who work in a hospice environment, in part because many hospices de-emphasize the medical model in favor of a model in which nursing autonomy prevails, tend to be more independent and decisive than their colleagues (Amenta, 1984). Vincent and

Garmson-Peace (1986) discovered that hospice nurses tended to show higher self-actualization scores than non-hospice nurses. Finally, as we have noted earlier, improvements in staff morale can be traced to specific, targeted efforts to reduce staff stress through counseling and other support systems (Gray-Toft, 1980).

#### Costs and Outcomes of Hospice Care: Conclusion

Much of the evidence reviewed in this section supports the argument that hospice has been a cost-effective method of providing care to terminally-ill patients; hospice care reimbursed under the Benefit is less expensive for Medicare than non-hospice care for most patients, particularly in freestanding and HHA-based hospices. Although many of the patterns observed in earlier studies characterize patient utilization under the Benefit (relatively low use of inpatient services, for example), findings on hospice cost "savings" are inconclusive at present. Data from FY86 on the size and significance of the Benefit's cost advantage under a "permanent" Medicare Hospice Benefit will further test these conclusions.

In spite of major differences in the methods, measures and even questions asked among studies of hospice and conventional care, two points of consensus have emerged:

- Hospice care has been less costly than conventional care in the last month of life, during the period when most hospice utilization is concentrated.
- Quality of life outcomes in hospice are no worse than in conventional care; in some types of hospices for some types of patients, they appear to be better, and in others the evidence is not conclusive.

Some features of the Medicare Benefit seem likely to assure that participating hospices will continue to provide cost effective services. The Medicare reimbursement cap and restrictions on inpatient utilization should lead hospices to stress home placement. Program requirements for

participating hospices (professional management responsibility, core services, quality assurance) impose conditions that, although onerous for many hospices, should help maintain or improve clinical standards of care.

Although contentions of some that the hospice cost advantage for Medicare or other payers may disappear have not been born out, caution on this issue is still advisable. If terminally-ill cancer patients who had never previously used medical services intensively are increasingly attracted into the Hospice Benefit, Medicare payments for treating these patients may be higher in hospices than they would have been in conventional care. The average intensity of conventional care treatment may be changing as well; if physicians have grown more flexible in their attitudes toward families' preferences for a palliative approach, then more and more patients in "conventional" settings may be adopting a hospice-like (and less expensive) regimen of care. Evidence that home has increasingly become the site of death for terminally ill cancer patients supports this position. Medicare's PPS for hospitals may also have encouraged some physicians to modify their practice toward home placement. Finally, if Medicare hospice payment rates rise over time and attract providers that are less efficient in providing care than early participants, costs to all payers, including Medicare, are likely to rise.

6.6      Are payment rates and conditions under the Benefit fair and equitable?

Beginning with HCFA's publication of proposed rules in 1983 and continuing through the first year of implementation, observers have expressed concerns about the effect of the reimbursement system on provider participation in the Benefit and on the future evolution of the hospice movement. Some features of the system that many initially felt to be objectionable seem to have achieved acceptance. The prospective per diem

rates themselves, although initially challenged as inappropriate given the lack of baseline cost data on hospices, now constitute the framework for discussion. Critics now question the adequacy of the rates, rather than their prospective nature. Since passage of COBRA, in which each daily rate was increased by \$10, criticism has diminished. Many other issues remain unresolved however, and one of the tasks of this evaluation will be to provide information to support retention or change in specific parts of the payment methodology.

Several objections to the current system have been raised:

- The routine home care rate is too low: it does not compensate for the expensive components of home hospice care, such as prescription drugs.
- Other per diem rates are also too low: concerns about general and respite inpatient rates, and about the rate for continuous home care have been expressed, although less strongly than for routine home care.
- As written, the law and regulations favor home health agency based hospices and freestanding community hospices over hospices with hospital affiliation.
- The payment methodology fails to cover adequately certain services of particular importance in hospice care; outpatient drugs, dietary and nutritional counseling and bereavement counseling.

Evidence on these questions comes from prior research and from audited cost reports submitted by 36 Medicare certified hospices in FY84. This evidence should be used with caution. Out of 84 cost reports submitted during the first year of the Benefit (from a population of 146 certified providers), these 36 contained what HCFA staff determined to be reliable data, following an intensive, post-audit review. They are not necessarily representative of the FY84 cohort of certified hospices. It is expected that FY85 and 86

reports from a more representative group of hospice providers will be available for the final Evaluation Report.

### 1. The Routine Home Rate

The payment rate for routine home care has been closely scrutinized, partly because most of the patient days of service provided by certified hospices will be in this category. The history of the Benefit reflects a continuing struggle over the level of this rate.

HCFA set a routine home care rate of \$46.25 in its final rules for the Hospice Benefit published on December 16, 1983. Because this represented a reduction from what Congress and many hospice advocates considered a low rate in the Notice of Proposed Rules published in August (\$53.17), the response was immediate and generally negative. The lower rate prevailed from November, 1983 through September, 1984, when Congress, with considerable support from the hospice community, raised the rate back to its previous, higher level.

Most of the component parts of the routine home care rate were based on costs incurred under the HCFA hospice demonstration. Much of the difference between the \$53 and the \$46 rates was due to revisions in estimates of visits per day from traditional home health providers (nursing, home health aides services, social service/therapies). The \$53 figure was based on early (1984) returns on about half of the demonstration patients and providers, whereas the lower \$46 figure included more complete information on over 3800 demonstration patients and the 1982 cost reports of the 25 participating hospices.

Critics have argued that the routine home care rate is too low to pay for the complex, intensive range of home care services required for most hospice patients. The National Hospice Organization, in testimony before the

Senate Finance Committee, presented estimates based on data from 119 certified hospices, that the actual cost per home day was about \$70. It is difficult to evaluate this estimate, because the NHO provided no indication of how responding hospices made their computations.

Estimates from previous literature on hospice routine home costs range from \$46 to \$58 per home day. Among the hospices that participated in the HCFA demonstration, 8 out of 25 showed average costs (in 1982 dollars) higher than the regionally-adjusted rate per home day. Of these, six were non-bedded hospices and two were hospital-based or bedded freestanding hospices.

Based on limited cost report information from FY 84, the average routine home care cost per diem in certified hospices was below the \$53 rate (see Table 24). Cost differences were slight between freestanding (\$48), and hospital-based hospices (\$47). SNF-based averages (\$143, for only three providers with useable data) seemed unaccountably high. Under the routine home care rates that prevailed in FY84, 19 of the 36 reporting certified hospices "lost" on Medicare days; for these providers costs ranged from \$1 to \$148 per day more than their regionally-adjusted payment rates. The rest broke even or earned up to \$45 per day of positive net revenue on Medicare routine home care days.

Adding \$10 to the rate would have allowed 7 "losers" to break even or earn positive net revenues on Medicare routine home care. Twelve of the hospices incurred higher costs for routine home care than they would have received under the higher payment rates.

## 2. The Inpatient (Respite and General) Care Rates

The inpatient respite rate, based on Medicare estimates of routine costs in skilled nursing facilities (plus components for drugs, supplies

Table 24

FY 84 Medicare Certified Hospices  
Routine Home Care Costs and Payment Rates

| Hospice  | Routine<br>Home Care Cost<br>Per Day | FY 84 Payment<br>- Cost | FY 86 Payment<br>- Cost |
|--|--------------------------------------|-------------------------|-------------------------|
| <u>HHA-Based (<math>\bar{x} = \\$67</math>; Median = \$46)</u>   |                                      |                         |                         |
| 1  | \$197                                | (\$148)                 | (\$138)                 |
| 2  | 168                                  | (115)                   | (105)                   |
| 3  | 79                                   | (27)                    | (17)                    |
| 4  | 75                                   | (22)                    | (12)                    |
| 5  | 66                                   | (19)                    | (9)                     |
| 6  | 50                                   | (10)                    | 0                       |
| 7  | 46                                   | 2                       | 12                      |
| 8  | 45                                   | 9                       | 19                      |
| 9  | 43                                   | 10                      | 20                      |
| 10   | 42                                   | 11                      | 21                      |
| 11   | 34                                   | 15                      | 25                      |
| 12   | 32                                   | 13                      | 23                      |
| 13   | 31                                   | 15                      | 25                      |
| 14   | 25                                   | 20                      | 30                      |
| <u>Hospital-Based (1 provider; \$47)</u>                         |                                      |                         |                         |
|  |                                      | (\$1)                   | \$9                     |
| <u>SNF-Based (<math>\bar{x} = \\$143</math>; Median = \$146)</u> |                                      |                         |                         |
| 1  | \$165                                | (\$107)                 | (\$97)                  |
| 2  | 146                                  | (97)                    | (87)                    |
| 3  | 119                                  | (61)                    | (51)                    |

Table 24 (continued)

| Hospice   | Routine<br>Home Care Cost<br>Per Day | FY 84 Payment<br>- Cost | FY 86 Payment<br>- Cost |
|---|--------------------------------------|-------------------------|-------------------------|
| <u>Freestanding</u> ( $\bar{x} = \$48$ ; Median = \$50) |                                      |                         |                         |
| 1   | \$83                                 | (\$34)                  | (\$24)                  |
| 2   | 71                                   | (20)                    | (10)                    |
| 3   | 70                                   | (27)                    | (17)                    |
| 4   | 64                                   | (14)                    | (4)                     |
| 5   | 62                                   | (10)                    | 0                       |
| 6   | 58                                   | (6)                     | 4                       |
| 7   | 55                                   | (8)                     | 2                       |
| 8   | 52                                   | (6)                     | 4                       |
| 9   | 51                                   | (8)                     | 2                       |
| 10  | 49                                   | 0                       | 10                      |
| 11  | 48                                   | 3                       | 13                      |
| 12  | 48                                   | 3                       | 13                      |
| 13  | 37                                   | 13                      | 23                      |
| 14  | 35                                   | 16                      | 26                      |
| 15  | 32                                   | 16                      | 26                      |
| 16  | 30                                   | 20                      | 30                      |
| 17  | 19                                   | 31                      | 41                      |
| 18  | 0.2                                  | 45                      | 55                      |

Source: FY 84 HCFA Medicare Certified Hospice Cost Reports.

Note: Negative (Payment - Cost) values are in parentheses.

equipment and the services of the interdisciplinary team) received almost no attention, partly because few hospices have had experience with respite care in the past. In FY84, only 6 certified hospices incurred costs for respite care during the first year of the Hospice Benefit (Table 24). Less than one half of one percent of all Benefit days were respite care days; this percentage was virtually the same in the four hospice types. Due in part to infrequency of occurrence, respite costs under the Benefit have been highly variable. For example, the average respite day cost \$86 in freestanding hospices and \$161 in 3 HHA-based hospices. For the 6 hospices involved, per diem costs always exceeded FY84 payment rates. Adding \$10 to the daily rate created one winner, a freestanding hospice that would have earned \$3 per respite day in net revenue.

The general inpatient rate was estimated from data on 1981 costs experienced by hospital-based and bedded freestanding hospices in the HCFA demonstration. The general inpatient rate, which covers room and board plus an inpatient ancillary service component, represents an adjustment downward from actual observed costs, to compensate for the fact that demonstration hospices tended to be affiliated with large and expensive urban teaching hospitals. The routine component (\$171) is still higher than average reimbursement for cancer patients' routine inpatient hospital charges for the U.S. during 1982 (\$156). Hospice ancillary costs (laboratory, pharmacy, chemotherapy, oxygen and other services) were estimated to be \$45 per day. This represents about 40 percent of the average ancillary costs of treating Medicare demonstration patients in hospitals (for those hospices that did not provide inpatient services directly). The general inpatient rate of \$271 include routine and ancillary components and an inflation factor to bring the

1981 estimates to 1984 values. COBRA increased this rate to \$281, effective April 1, 1986.

Past estimates of total inpatient costs per day (routine and ancillary) in hospice vary widely. The 1981 inpatient cost in the least expensive HCFA demonstration hospice was \$177 per patient day, and the most expensive program cost \$523 per patient day. Estimates from Kay (1981), based on three sites, range from \$143 to \$250 per patient day. NHS findings suggest that HHA-based hospices, faced with the need to contract for inpatient services, will have greatest difficulty coping with the present rate. Patients in five of 14 non-bedded hospices in the HCFA demonstration incurred higher costs in 1982 for a day of inpatient care than the \$271 general inpatient rate; in contrast, only 2 of 11 hospital-based programs experienced higher costs. Based on its 1984 survey, the NHO estimated that the actual inpatient costs experienced by Medicare-certified hospices was \$368 per day, compared to the \$271 per diem rate.

During FY84, 18 of the 36 Medicare-certified hospices used in this analysis incurred general inpatient costs per diem that exceeded regionally-adjusted payment rates. Losses ranged from \$4 to \$1512 per day (Table 25). Nine hospices did not report any costs allocated to general inpatient care. HHA-based hospices reported the highest average costs for inpatient care (\$529 per diem), with a median of \$406; costs of freestanding hospices were similar, averaging \$500 per day,, with a median of \$550. Adding \$10 to the general inpatient rate would have converted three losers to winners. Most hospices lost on general inpatient care under both payment rates.

Table 25

**FY84 Medicare Certified Hospices**  
**General Inpatient and Inpatient Respite**  
**Costs and Payment Rates**

| Hospice  | General Inpatient Cost Per Day | FY84 Payment - Cost | FY86 Payment - Cost | Inpatient Respite Cost Per Day | FY84 Payment - Cost | FY86 Payment - Cost |
|--|--------------------------------|---------------------|---------------------|--------------------------------|---------------------|---------------------|
| <b>HHA-Based (<math>\bar{X} = \\$529</math>; Median = \$406)</b> |                                |                     |                     |                                |                     |                     |
| (4 providers: Cost = 0)  |                                |                     |                     |                                |                     |                     |
| 1  | \$1,801                        | (\$1,512)           | (\$1,502)           | 1                              | \$207               | (\$145)             |
| 2  | 816                            | (545)               | (535)               | 2                              | 185                 | (131)               |
| 3  | 523                            | (242)               | (232)               | 3                              | 90                  | (29)                |
| 4  | 492                            | (181)               | (171)               |                                |                     |                     |
| 5  | 428                            | (119)               | (109)               |                                |                     |                     |
| 6  | 384                            | (117)               | (107)               |                                |                     |                     |
| 7  | 380                            | (69)                | (59)                |                                |                     |                     |
| 8  | 214                            | 92                  | 102                 |                                |                     |                     |
| 9  | 195                            | 66                  | 76                  |                                |                     |                     |
| 10   | 57                             | 218                 | 228                 |                                |                     |                     |
| <b>Hospital-Based</b>  |                                |                     |                     |                                |                     |                     |
| (1 provider: Cost = 0)   |                                |                     |                     |                                |                     |                     |
| <b>SNF-Based (<math>\bar{X} = \\$253</math>; Median = \$290)</b> |                                |                     |                     |                                |                     |                     |
| 1  | \$385                          | (\$51)              | (\$41)              | 1                              | \$276               | (\$218)             |
| 2  | 290                            | (4)                 | 6                   |                                |                     |                     |
| 3  | 84                             | 251                 | 261                 |                                |                     |                     |
| <b>Hospital-Based</b>  |                                |                     |                     |                                |                     |                     |
| (1 provider: Cost = 0)   |                                |                     |                     |                                |                     |                     |
| <b>SNF-Based</b>   |                                |                     |                     |                                |                     |                     |
| 1  | \$208                          |                     |                     |                                |                     |                     |

Table 25 (continued)

**FY84 Medicare Certified Hospices**  
**General Inpatient and Inpatient Respite**  
**Costs and Payment Rates (Cont'd)**

| Hospice                                      | General Inpatient<br>Cost Per Day | FY84 Payment<br>- Cost | FY86 Payment<br>- Cost | Inpatient Respite<br>Cost Per Day | FY84 Payment<br>- Cost | FY86 Payment<br>- Cost | Payment |
|--|-----------------------------------|------------------------|------------------------|-----------------------------------|------------------------|------------------------|---------|
| <b>Freestanding (4 providers: Cost = 0)</b>  |                                   |                        |                        |                                   |                        |                        |         |
| <b>Freestanding (16 providers: Cost = 0)</b> |                                   |                        |                        |                                   |                        |                        |         |
| 1  | \$820                             | (\$527)                | (\$517)                | 1                                 | \$104                  | (\$45)                 | (\$35)  |
| 2  | 727                               | (423)                  | (413)                  | 2                                 | 68                     | (7)                    | 3       |
| 3  | 709                               | (422)                  | (412)                  |                                   |                        |                        |         |
| 4  | 671                               | (377)                  | (367)                  |                                   |                        |                        |         |
| 5  | 662                               | (376)                  | (366)                  |                                   |                        |                        |         |
| 6  | 618                               | (325)                  | (315)                  |                                   |                        |                        |         |
| 7  | 551                               | (257)                  | (247)                  |                                   |                        |                        |         |
| 8  | 549                               | (256)                  | (246)                  |                                   |                        |                        |         |
| 9  | 488                               | (236)                  | (226)                  |                                   |                        |                        |         |
| 10   | 477                               | (185)                  | (175)                  |                                   |                        |                        |         |
| 11   | 305                               | (8)                    | 2                      |                                   |                        |                        |         |
| 12   | 285                               | (5)                    | 5                      |                                   |                        |                        |         |
| 13   | 134                               | 168                    | 178                    |                                   |                        |                        |         |
| 14   | 9                                 | 259                    | 269                    |                                   |                        |                        |         |

Source: FY84 HCFA Medicare Certified Hospice Cost Reports

Note: Negative (Payment-Cost) values are in parentheses

### 3. Continuous Home Care Rates

The Hospice Benefit rules defined conditions when continuous home care are appropriate as "...periods of crisis where predominantly skilled continuous care is necessary to achieve palliation or management of the patient's acute medical symptoms, and only as necessary to maintain the patient at home." Need for caregiver respite was not considered an appropriate justification for continuous home care; instead carefully limited respite care was to be provided in an inpatient facility. Continuous home care is designed to substitute for general inpatient care.

A full 24-hour payment for continuous care is presently set at \$368.67, but payments of \$15.36 per hour actually reflect the number of hours of service provided, above a minimum of eight hours. A three-tiered system of rates, depending on how many hours of service were supplied, was abandoned after the system was criticized as too cumbersome during rulemaking.

Major hospice concerns regarding the present rules on continuous care payments center on rate adequacy, and implied guidelines for intermediaries to use in judging the appropriateness of a continuous care bill; in particular, the requirement of a substantial skilled nursing component worries hospices that would prefer to manage patients with a less expensive mix of home health aide and skilled nursing services. Hospices that have complained about long lags between claim submissions and payments have pointed out that intermediaries are paying particularly close attention to the medical necessity for continuous care claims.

Data from HCFA's demonstration were used to set the original continuous care rates. Components include nursing, therapy, drugs, supplies, and equipment and a portion to cover services of the interdisciplinary team. Like inpatient respite care, continuous care was infrequently used in demonstration

hospices. Over half of the continuous care hours claimed in the demonstration were provided by one hospice. Also, the literature on hospice and terminal illness provides no evidence on costs and patterns of utilization of intensive nursing care at home.

Over time, cost reports from certified hospices will provide data to test the fairness of this rate, and will also make it possible to see whether funding continuous care has generated savings in inpatient days. However, some preliminary observations are possible. Round-the-clock care at home is much more expensive than general inpatient care. In order to just match payments for a general inpatient day, continuous care days would have to be billed for no more than 18 hours of care (\$15.36 per hour times 18.29 hours equals \$281). Hospices have few obvious incentives to limit hours of service provided or to recommend alternatives to continuous care. Several considerations make continuous care attractive:

- Using continuous care makes it possible to maintain services at home, regardless of changes in the patient's medical needs;
- Continuous care days are not capped, whereas general and respite inpatient days are (at 20 percent of total patient days);
- The inpatient rate is not adjusted for variations in intensity, whereas the continuous care payments increase with the number of hours of service provided;
- To qualify for certification, many hospices must contract for inpatient care and pay for costs over which they have little control. However, continuous care can be provided by core services staff over which the hospice can exercise direct budget control; and
- Clinical control during periods of intensive care is more feasible through continuous home care than through contract inpatient care.

Two factors might limit hospice preference for continuous care over general inpatient care: the cost of providing services and the expectation of

long delays and disputes with intermediaries over appropriateness. Based on its survey of certified hospices, the National Hospice Organization claimed that continuous home care cost an average of \$466.56, compared to the maximum payment rate of \$358.67; there is no way to validate this estimate without information on survey response rates, the computational methods used by individual hospices and other supporting data. There is evidence that hospices may have hesitated to submit continuous care claims, but at this time it is impossible to disentangle the effects of lags in intermediary decisions from low volumes of claims.

Findings from the 36 available FY84 Medicare-certified hospice cost reports support the NHO's contention that costs of continuous care exceed Medicare payments. Overall, continuous care days made up three percent of total days of care furnished during the first year of the Medicare Hospice Benefit. Many certified hospices lost as much or more on continuous care as they did on general inpatient care in FY84; only 2 hospices spent less per diem than their regionally adjusted payment rates (Table 26). Among those that spent in excess of payment, losses ranged from \$29 to \$1687 per diem. Freestanding hospice costs for continuous care averaged \$1203 per diem. Hospital-based and SNF-based hospices averaged over \$1000 per diem. HHA-based hospices incurred the lowest daily costs, at \$1046. As with other infrequently used services (general and respite inpatient care), the \$10 rate increase included in COBRA would not have changed the distribution of winners and losers in continuous care for Medicare patients.

4. Does the current legislation favor one type of hospice over another?

Critics of the Medicare Hospice Benefit charge that conditions of participation and the payment methodology have been written to favor hospices with comparative advantage in home care. Predictions that most certified

Table 26

**FY 84 Medicare Certified Hospices**  
**Continuous Home Care Costs and Payment Rates**

| Hospice  | Continuous<br>Care Cost<br>Per Day | FY 84 Payment<br>- Cost | FY 86 Payment<br>- Cost |
|--|------------------------------------|-------------------------|-------------------------|
| <u>HHA-Based</u> ( $\bar{x} = \$1,046$ ; Median = \$1,059) |                                    |                         |                         |
| (1 provider: Cost = 0)                                     |                                    |                         |                         |
| 1  | \$1,898                            | (\$1,484)               | (\$1,474)               |
| 2  | 1,634                              | (1,255)                 | (1,245)                 |
| 3  | 1,560                              | (1,202)                 | (1,192)                 |
| 4  | 1,433                              | (1,018)                 | (1,008)                 |
| 5  | 1,385                              | (1,020)                 | (1,010)                 |
| 6  | 1,159                              | (746)                   | (736)                   |
| 7  | 1,059                              | (657)                   | (647)                   |
| 8  | 984                                | (599)                   | (589)                   |
| 9  | 805                                | (397)                   | (387)                   |
| 10   | 514                                | (162)                   | (152)                   |
| 11   | 510                                | (95)                    | (85)                    |
| 12   | 383                                | (71)                    | (61)                    |
| 13   | 271                                | 103                     | 113                     |
| <u>Hospital-Based</u> (1 provider; \$1,164)                |                                    | (\$813)                 | (\$803)                 |
| <u>SNF-Based</u> ( $\bar{x} = \$1,510$ ; Median = \$1,510) |                                    |                         |                         |
| (1 provider: Cost = 0)                                     |                                    |                         |                         |
| 1  | \$1,655                            | (\$1,206)               | (\$1,196)               |
| 2  | 1,365                              | (985)                   | (975)                   |

Table 26 (continued)

| Hospice   | Continuous<br>Care Cost<br>Per Day | FY 84 Payment<br>- Cost | FY 86 Payment<br>- Cost |
|---|------------------------------------|-------------------------|-------------------------|
| <u>Freestanding</u> ( $\bar{x} = \$1,203$ ; Median = \$968) |                                    |                         |                         |
| (4 providers: Cost = 0)                                     |                                    |                         |                         |
| 1   | \$2,078                            | (\$1,687)               | (\$1,677)               |
| 2   | 1,949                              | (1,536)                 | (1,526)                 |
| 3   | 1,909                              | (1,518)                 | (1,508)                 |
| 4   | 1,463                              | (1,072)                 | (1,062)                 |
| 5   | 1,359                              | (979)                   | (989)                   |
| 6   | 1,269                              | (873)                   | (863)                   |
| 7   | 1,051                              | (693)                   | (683)                   |
| 8   | 885                                | (497)                   | (487)                   |
| 9   | 878                                | (476)                   | (466)                   |
| 10  | 757                                | (376)                   | (366)                   |
| 11  | 704                                | (372)                   | (362)                   |
| 12  | 568                                | (163)                   | (153)                   |
| 13  | 420                                | (29)                    | (19)                    |
| 14  | 353                                | 18                      | 28                      |

Source: FY 84 HCFA Medicare Certified Hospice Cost Reports.

Note: Negative (Payment-Cost) values are in parentheses.

hospices will be HHA-based or freestanding, based both on this interpretation of the incentives in the regulations and on results of an early survey of hospice intentions, have been largely borne out (Kusserow, 1984).

Features of the Benefit that favor a home care orientation have been discussed earlier in this section:

- The 20 percent limit on total inpatient days;
- A core services requirement for direct provision of skilled nursing and counseling services; and
- A fixed budget cap that forces hospices to manage patient placement efficiently.

Recent increases in payment rates also tend to favor hospices that can manage patients most effectively at home. The COBRA increase in all four daily rates by \$10 has the largest proportional impact on routine home care and inpatient respite care rates (increases of 18.8 percent and 18 percent respectively). The financial impact of the respite care increase, if use of respite services by hospice patients remains at past low levels, will be minimal. Cost reports for certified hospices indicate that respite made up less than one percent of total patient days. Percentage increases in the payment rates for the more costly general inpatient and continuous home care services would be considerably smaller (4 percent and 2.8 percent). Given the built-in limits on inpatient billing and the stringent intermediary review to which continuous care claims tend to be subject, small rate increases for these services are unlikely to have much effect on utilization.

In the final analysis, a conclusion that there is bias in the Hospice Benefit that favors one provider model over another must be based on experience. Evidence from FY84 is inconclusive. There are too few cost reports from each hospice category to permit any generalizations. Further analysis of recent data will be needed to capture effects of changed

incentives when per diem rates were raised and the sunset provision eliminated.

During the coming year, as data on both certified and noncertified hospices are collected and analyzed, it will be possible to evaluate the decisions specific types of hospices made regarding participation in the Benefit program, and the relative importance of per diem payment rates in those decisions.

6.7        Are Certain Service Categories Appropriately Reimbursed Under the Benefit?

The prospective per diem rates adopted for the Medicare Hospice Benefit were designed to pay for a range of specific services delivered in home or inpatient settings. Each daily rate included service components such as drugs, supplies, equipment, the services of an interdisciplinary team, nursing visits, counseling and therapy services. The overall adequacy of each rate depends in part on whether the costs of some components, such as drugs, vary widely among hospices, putting some programs at a severe financial disadvantage. Bereavement counseling represents a unique case. Hospices must provide bereavement support to be certified, but the rates make no explicit provision for this service, and hospices are forbidden by law from billing Medicare for it.

Section 122(j)(1) of the law that created the Medicare Hospice Benefit mandates "...an evaluation of the inclusion of payment for outpatient drugs, an evaluation of the need to alter the method of reimbursement for nutritional, dietary, and bereavement counseling as hospice care..." This section of the report describes: 1) the current provisions for these services under the Benefit; 2) rates of utilization and cost for drugs, dietary/nutritional and bereavement services in previous hospice research; 3) findings from the first year of the Benefit, based on the 36 hospices (out

of a possible 84) that submitted usable, audited cost reports. The reader should view the figures presented here with some caution, because this set of "good" cost reports does not represent a valid random sample of FY84 Medicare certified hospices. The final report will include FY85 and 86 data from certified and noncertified cost reports.

#### **1. Outpatient Drugs: Current Provisions of the Benefit**

Hospice beneficiaries' use of prescription drugs and biologicals is paid for under the Medicare Benefit in two ways: inpatient pharmacy charges are compensated through the general inpatient care per diem, and outpatient prescription drug charges are included in the routine and continuous home care rates. HCFA estimated drug costs per hospice home day based on average payments under the demonstration, adjusted downward for the 5 percent copayment that hospices were allowed by law to collect.<sup>1</sup>

Drug therapy has always been a critical part of hospice care. Given the U.S. hospice emphasis on home placement, it was anticipated that many patients would receive most of their prescription drugs on an outpatient basis. Two areas of concern will be addressed in the evaluation:

- Is it fair to hospices, and cost effective to Medicare, to pay for outpatient drugs as part of the home care per diem?
- What effect (on hospice revenues and patient utilization) does the drug copayment provision have?

Data on Hospice Beneficiaries' use of outpatient drugs are not available. Only costs allocated to outpatient drugs on Medicare-certified hospices' cost reports provide any indication of aggregate utilization

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<sup>1</sup>Certified hospices need not exercise this right to collect outpatient drug copayments. However, if a hospice plans to collect copayments, it must first submit a list of drugs that will be prescribed and their prevailing charges to its intermediary.

levels. Much of the following discussion of patient drug use relies on prior research, with particular emphasis on findings from the National Hospice Study.

#### Outpatient drug utilization

Even though the founders of the hospice movement recommended massive doses of analgesic medication to prevent chronic pain, studies show that rates of use as well as dosage levels have been quite variable among hospice programs and among patients. The major drug types used by hospice patients are analgesics (for pain control), anti-emetics (for control of gastro-intestinal symptoms, such as nausea) and anti-depressants (for control of mood disturbances).<sup>1</sup>

Variations in the prescription and use of analgesics reflects many factors, including the experience and perceptions of clinicians. Walsh and Saunders (1984) reflect the British tradition when they recommend doses of oral morphine from 10 to 50 milligrams every four hours for mild pain not localized in the patient's bones. In contrast, Geltman and Paige (1983) prescribe less intensive dosages: morphine is not called for when the pain is "mild," and is applied only in doses up to 20 milligrams every four hours for "moderate" pain. More recent literature calls for a graduated response across a range of non-narcotic and narcotic drugs as pain increases in intensity (Levy, 1985; Takeda, 1985). There appear to be important differences in the use of drugs between home and inpatient hospice settings:

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<sup>1</sup>The use of controlled substances, such as heroin, widely advocated in Great Britain for combatting severe pain of terminally ill patients has not received much support in the United States; research indicates that, although the speed with which narcotics act to reduce pain may exceed that of non-narcotic analgesics, use of the latter provides satisfactory pain relief without raising major ethical and legal issues (Brandt, 1984; Takeda, 1985).

- It is suspected, based on evidence of self-reported pain and studies of hospice staff training in pharmacology, that drug use may be less well controlled in home settings than in patient settings (Kassakian, et al., 1979; Galt and Galt, 1984). This suspicion is supported by findings from the HCFA demonstration that patients who initiated their own treatments were less successful in controlling pain than patients treated under supervision. (Morris, Suizza and Sherwood, op cit.);
- In the HCFA demonstration, patients in bedded hospices were more likely to receive analgesic prescriptions than were patients in non-bedded hospices (90 and 66 percent were respectively), (Goldberg, et al., in press);
- Even though the percentage of patients with prescriptions was higher in bedded demonstration hospices, actual use was lower: 22 percent of patients in bedded hospices who had prescriptions for analgesic drugs did not use them, whereas all patients in non-bedded hospices used analgesics when prescribed (Goldberg, et al., in press).

In general, U.S. hospice patients rely less on analgesic drugs than do British patients. If low dosages reflect conservatism on the part of U.S. clinicians or limits on use of complex drug protocols in home care settings, then greater experience and more intensive training of primary care persons may lead to higher utilization in the future.

Hospices have been less disposed to prescribe drugs for the control of symptoms other than pain. The prevalence of nausea and vomiting at some time during the last weeks of a terminal illness has been estimated to be over 50 percent (Wachtel, et al., 1986); yet only 32 percent of those patients that reported nausea during a recent study received a prescription to control these symptoms (Reuben and Mor, unpublished). These findings were consistent across hospices by type, and between hospice and conventional care.

The prevalence of mood disturbance among terminally ill patients is difficult to substantiate; Goldberg (1981) estimated that about 20 percent of cancer patients exhibit signs of depression although another study estimates that up to 50 percent do (Stedeford, 1981). However, many studies confirm

that fewer than 5 percent of terminally ill patients whether in hospice or conventional care receive prescriptions for anti-depressant medications during the last weeks of life (Goldberg and Mor, in press; Goldberg, et al., 1973; Derogatis et al., 1983). Levy and Catalano (1985) recommend various antidepressants for seriously affected patients, but there is little evidence that use of drugs to control mood disturbance has increased.

#### Drug costs and payment

There has been little available evidence about the costs of drugs used in hospice and conventional care. The estimate of \$0.95 per home day<sup>1</sup> used to construct a routine home care payment rate, was based on drug claims from the HCFA demonstration and represents 1.7 percent of the routine home care rate.

An analysis for the Hospice Benefit Evaluation of outpatient drugs claims submitted during the HCFA demonstration showed that the average charge home day for patients with one or more prescriptions was \$3.17 (Medicare Hospice Benefit Evaluation FY84 Technical Report). These charges reflected prices per prescription that varied across the five most common drug categories from \$19.38 for codeine, morphine and opium derivatives (27.3 percent of all prescriptions) to \$9.83 for diuretics (4.9 percent of prescriptions) (Table 27). Estimates from this analysis of the HCFA Outpatient Drug data yielded higher average charges than the \$0.95 per home day figure that HCFA used to set home care payment rates. This is because all patients with no prescriptions were dropped from the Evaluation's reanalysis; it was impossible to tell how many actually did not use outpatient drugs and

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<sup>1</sup>HCFA used an estimate of \$1.06 to set the routine home care per diem of \$46.25 that prevailed during FY1984. The \$0.95 figure applied to an earlier rate (\$53.17) which Congress legislated to be the effective per diem from October 1, 1984.

Table 27

HCFA Demonstration Prescription Drugs: Numbers, Percentages and  
Average Prices Per Prescription, by Drug Type<sup>1</sup>

| Code | Drug Categories  | N<br>Prescriptions | %<br>Total | Average<br>Price |
|------|--|--------------------|------------|------------------|
| 001  | Analgesics - Non-narcotic  | 833                | 3.2        | \$13.96          |
| 002  | Codeine, Morphine and Opium Derivatives<br>Synthetics and Combinations | 7170               | 27.3       | 19.38            |
| 003  | Potent Synthetics and Combinations                                     | 561                | 2.1        | 13.55            |
| 004  | Antibacterials and Antiseptics   | 591                | 2.2        | 14.49            |
| 005  | Antibiotics  | 1073               | 4.1        | 17.66            |
| 006  | Anticoagulants   | 96                 | 0.4        | 14.87            |
| 007  | Anticonvulsants  | 408                | 1.6        | 10.63            |
| 008  | Antidepressants  | 532                | 2.0        | 10.21            |
| 009  | Antidiarrheals   | 204                | 0.8        | 9.68             |
| 010  | Anti-inflammatory Agents - Steroids and<br>Combinations                | 1305               | 5.0        | 17.08            |
| 011  | Anti-inflammatory Agents - Other                                       | 334                | 1.3        | 19.32            |
| 012  | Antinauseants  | 2016               | 7.7        | 12.85            |
| 013  | Antineoplastics  | 317                | 1.2        | 34.37            |
| 014  | Antispasmodics and Anticholinergics                                    | 467                | 1.8        | 14.45            |
| 015  | Bronchial Dilators   | 655                | 2.5        | 11.82            |
| 016  | Central Nervous System Stimulants                                      | 35                 | 0.1        | 6.77             |
| 017  | Cough Preparations with Narcotics                                      | 178                | 0.7        | 9.24             |
| 018  | Decongestants, Expectorants and<br>Combinations                        | 183                | 0.7        | 9.14             |
| 019  | Diuretics  | 1291               | 4.9        | 9.83             |
| 020  | Electrolytes   | 449                | 1.7        | 9.52             |
| 021  | Hormones   | 258                | 1.0        | 13.60            |
| 022  | Hypnotics  | 406                | 1.5        | 7.92             |
| 023  | Laxatives  | 485                | 1.8        | 8.63             |
| 024  | Sedatives - Barbiturates   | 253                | 1.0        | 9.08             |
| 025  | Sedatives - Non-Barbiturates   | 450                | 1.7        | 8.61             |
| 026  | Tranquilizers  | 1366               | 5.2        | 11.19            |
| 027  | Other Prescription Drugs and Biologicals                               | 4372               | 16.6       | 13.39            |
|      | 26,288   | 100.0              |            | \$14.85          |

<sup>1</sup>Represents prescriptions received by 2530 patients used in the analysis.

Source: HCFA ODR Drug File.

how many were simply missing claims data. Patients with no prescriptions were retained in HCFA's calculation.

The true figure is probably between the two average charge estimates. In the HCFA demonstration, "regular" Medicare hospice patients in non-participating hospices spent \$3.74 per home day out of pocket for outpatient drugs, supplies and equipment. Patients in the demonstration, for whom use of outpatient drugs was presumably reimbursed, still spent out of pocket between \$0.63 (in bedded hospices) and \$1.31 (in non-bedded hospices) for outpatient drugs, supplies and equipment. Assuming that the outpatient drug component of this expenditure was more than zero, then total outpatient drug expenditure (reimbursed and paid out-of-pocket) was probably higher than \$0.95 per home day.

#### Experience under the Benefit

Costs of outpatient drugs reported by Medicare-certified hospices in FY84 varied from a high \$5.79 per home day average in HHA-based hospices to \$1.21 for the single reporting hospital based hospice (Table 28). Median expenditures across all hospice types ranged from \$2.56 to \$3.18 per home day.

These data suggest two conclusions:

- HCFA's estimate of \$0.95 per home day for outpatient drugs was probably too low; the COBRA increase in payment rates by \$10 per diem will help relieve this problem for most hospices.
- A 5 percent copayment on outpatient drugs would not be a burden for most Hospice Benefit patients. Even the highest provider average cost per home day in FY84 (\$22.41) would call for a copayment of \$1.12 per home day, totaling about \$36 over the average 32 day enrollment period. Moreover, the cost to a certified hospice of administering a program to collect copayments would probably outweigh the gains. During the first two years of the Benefit, no certified hospice had submitted the required prescription lists to its intermediary preparatory to implementing a copayment system (HCFA staff, verbal communication).

Table 28

FY 84 Medicare Certified Hospices  
Costs of Outpatient Drugs

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| Hospice   | Outpatient Drug Cost Per Home Day<br>(Routine Plus Continuous Care) |
|---|---|
| <u>HHA-Based</u> ( $\bar{x} = \$5.79$ ; Median = \$3.18)<br>(3 providers: Cost = 0) |   |
| 1   | \$22.41 per home day  |
| 2   | 12.11   |
| 3   | 6.95  |
| 4   | 3.81  |
| 5   | 3.63  |
| 6   | 3.18  |
| 7   | 3.07  |
| 8   | 2.63  |
| 9   | 2.51  |
| 10  | 2.16  |
| 11  | 1.19  |

Hospital-Based (1 provider = \$1.21 per home day)

SNF-Based ( $\bar{x} = \$2.43$ ; Median = \$2.56)

|   |                     |
|---|---------------------|
| 1 | \$3.76 per home day |
| 2 | 2.56                |
| 3 | 0.96                |

Table 28 (continued)

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| Hospice  | Outpatient Drug Cost Per Home Day<br>(Routine Plus Continuous Care) |
|--|---|
| <u>Freestanding</u> $\bar{x} = \$3.50$ ; Median = \$2.80)<br>(2 providers: Cost = 0) |   |
| 1  | \$9.92 per home day   |
| 2  | 6.59  |
| 3  | 6.15  |
| 4  | 5.53  |
| 5  | 3.57  |
| 6  | 3.53  |
| 7  | 3.19  |
| 8  | 3.03  |
| 9  | 2.57  |
| 10   | 2.28  |
| 11   | 2.02  |
| 12   | 1.91  |
| 13   | 1.63  |
| 14   | 1.63  |
| 15   | 1.31  |
| 16   | 1.14  |

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Source: FY 84 HCFA Medicare Certified Hospice Cost Reports.

## 2. Dietary and Nutritional Counseling: Current Provisions of the Benefit

Under the Medicare Hospice Benefit, dietary counseling is included as a "core service," one that the hospice must provide directly rather than by contract. Hospices are paid for dietary counseling services under the Benefit through the per diem rates. The law stipulates that "dietary counseling, when required, must be provided by a qualified individual." Counseling, "...including dietary counseling", is apparently included as a covered hospice service, regardless of whether or not the individual who provides this service is professionally qualified.

### Utilization of dietary and nutritional counseling

Many hospice patients show symptoms that might be treated through diet control or special feeding techniques. In a 1981 study, loss of appetite occurred for 84 percent of patients; other less prevalent symptoms included nausea and vomiting (58 percent), and dry mouth and difficulty in swallowing (48 percent each) (Owen, 1982). Nutritional problems appear to be more prevalent in patients treated at home (Dixon et al., 1985). As has been the case with pain therapies, hospice inability to provide close supervision of primary care persons' activities may reduce the effectiveness of treatments.

Aggressive nutritional therapy has become more common in the treatment of conventional cancer patients (Burt, et al., 1984). The method of total parenteral nutrition (TPN) uses intravenous feeding exclusively to provide adequate nutrition. The process is expensive, averaging \$100 to \$200 per day for nutrient solutions. Its usefulness in home settings is debated. Lavery et al. (1980) and Weiss et al (1982) report evidence, based on small samples of patients, that TPN can be administered successfully at home and that it may be relatively cost effective compared to TPN in an inpatient setting.

Much of the debate over TPN concerns its alleged effect on patient survival. Hioki et al. (1984) report that TPN increased survival for some cancer patients. However, many investigators report no association between TPN and survival (Clamon et al., 1985; Freeman et al., 1982). Chlebowski (1985) and Nixon et al. (1981) report that TPN may have shortened survival among male patients with advanced colon cancer who had experienced little weight loss prior to receiving TPN treatment. Dewys' (1985) study of 199 cancer patients showed that median survival was twice as long for patients who had not lost weight; however, the study did not evaluate the role of TPN in this outcome.

In a 1985 survey of Medicare-certified and noncertified hospices, all responding certified hospices reported to JCAH that they provided dietary and nutritional counseling services to patients in the home; 91 percent provided these services in inpatient settings. (Please refer back to Table 4). Most noncertified hospices provided these services as well (86 and 84 percent, in home and inpatient settings). Certified hospices were more likely to provide dietary services through a registered dietician (82 and 72 percent, at home and in an inpatient setting) than were noncertified hospices (58 and 51 percent respectively). Thus, although reported frequencies of service provision were quite similar between the two hospice categories, certified hospices were more likely than noncertified hospices to turn to a qualified professional to counsel patients and families regarding diet and feeding practices.

#### Costs of dietary and nutritional counseling

There are limited valid data for predicting how much nutritional support services should cost. Moreover, these data suggest that hospices that report providing dietary services do not necessarily identify them in costing

total services. Only 4 of the 25 HCFA demonstration hospices billed for this service; for one, the cost per patient (\$78, 5.4 percent of that hospice's total expenditure) was clearly out of line with the other three that reported costs per patient of less than \$10.

#### Experience under the Benefit

Data from 36 audited FY84 cost reports confirm findings from the HCFA demonstration; only 3 out of 36 certified hospices that were analyzed reported costs of dietary counseling services. Total dietary expenditures per hospice were small, but the range was wide; among the three freestanding hospices that incurred these costs, the lowest was \$50 per hospice and the highest \$155. Average dietary costs per patient and per day are almost meaningless under these conditions. Dietary costs per home day ranged from \$0.01 to \$0.16.

Hospices will probably continue to approach the question of whether and under what circumstances TPN or other complex nutritional techniques should be used with considerable caution. The idea of adopting therapy that might prolong or shorten life is foreign to the hospice philosophy. With so little conclusive evidence on this point, it seems unlikely that traditional drug therapies will be replaced or even extensively supplemented by innovative techniques in nutritional management.

#### 3. Bereavement Counseling: Current Provisions of the Benefit

Bereavement support is central in hospice care, because it focuses on the family's adjustment to the patient's death. Congress recognized this fact when it made provision of bereavement services a criterion for attaining Medicare certification. However, the law specifically states that the costs of bereavement services cannot be reimbursed through Medicare; even though hospices treat the family as the unit of care, Medicare pays directly for

family services only when it includes a living, eligible Medicare beneficiary.

#### Utilization of bereavement services

Although there is wide agreement that the bereavement period may be accompanied by severe psychological and physical disturbance, there is little consistent evidence that formal intervention can reduce the prevalence and severity of these outcomes. Several voluntary, self-help approaches to coping with grief among nonhospice bereaved have been evaluated in a study by the Institute of Medicine; no differences have been detected in any measurable outcomes between participants and comparison groups (Osterweis *et al.*, 1984).

Hospice interventions with the bereaved range from loosely organized mutual support groups to regularly scheduled individual visits from health care professionals. JCAH (1987) found that the frequency of family contacts varied depending upon whether or not volunteers or social workers initiated the contacts. Volunteers had higher average numbers of contacts with families in both certified and noncertified hospices: 3.86 and 4.04 per family respectively, compared to 3.57 and 3.15, when contacts were initiated by social workers. The National Hospice Study showed that, in those cases for which hospices provided bereavement visits in the home, the visiting provider was typically a nurse (40 percent). Social workers (27 percent) and clergy (9 percent) were less commonly used in this role. Most visits were devoted to emotional counseling (60 percent). Only 14 percent of the visits included professional assessment of the bereaved person's physical or mental state (NHS, unpublished).

Not all bereaved families receive bereavement services. JCAH (1987) showed that all certified and 98 percent of noncertified hospices provided bereavement counseling. However, findings, from the National Hospice Study

show that nearly one-third of all families contacted within four months of a family member's death received no bereavement counseling; another 20 percent received only counseling on financial issues. (NHS, unpublished). Consistent with NHS results, Kane's (1986) study of V.A. hospice families showed that less than one quarter of bereaved families participated in bereavement counseling programs. As noted earlier in this report, formal support services may be inappropriate in some cases. An effective bereavement support program must distinguish families that require special attention during the period of grieving from families that are best left to adjust on their own.

#### Costs of bereavement counseling

There is only limited evidence from the literature on the costs hospices have incurred to provide bereavement counseling. Of the 23 HCFA demonstration hospices that billed for bereavement service, total costs per patient ranged from \$6 to \$148, and from less than one percent up to 6 percent of total expenditure (NHS, unpublished). Since much of the support work done for grieving families is provided through group sessions or by volunteers, many hospices probably found it difficult to estimate the appropriate costs.

#### Experience under the Benefit

Bereavement expenditure per case averaged \$80 for the 36 certified hospices that submitted usable cost reports in FY84 (Table 29). HHA-based and SNF-based hospices incurred expenses above the average (\$171 and \$105 respectively). Freestanding hospices' expenditures (\$23) were well below average. Lower average costs for freestanding hospices are consistent with NHS findings that freestanding hospices tend to rely more heavily than provider-based hospices on volunteers to provide bereavement services. The single hospital-based hospice that reported bereavement costs apparently spent \$3 per case (a total of \$45 spent on a patient census of 15).

Table 29

FY 84 Medicare Certified Hospices  
Costs of Bereavement Counseling

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| Hospice | Bereavement Counseling Cost Per Patient |
|---------|---|
|---------|---|

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HHA-Based ( $\bar{x} = \$171$ ; Median = \$138)

(6 providers: Cost = 0)

|   |                   |
|---|-------------------|
| 1 | \$331 per patient |
| 2 | 328               |
| 3 | 313               |
| 4 | 143               |
| 5 | 133               |
| 6 | 53                |
| 7 | 51                |
| 8 | 17                |

Hospital-Based (1 provider = \$3 per patient)

SNF-Based ( $\bar{x} = \$105$ ; Median = \$105)

(1 provider: Cost = 0)

|   |                   |
|---|-------------------|
| 1 | \$108 per patient |
| 2 | 101               |

Table 29 (continued)

| Hospice  | Bereavement Counseling Cost Per Patient |
|--|---|
| <u>Freestanding</u> ( $\bar{x} = \$30$ ; Median = \$28)<br>(4 providers: Cost = 0) |   |
| 1  | \$63 per patient                        |
| 2  | 56                                      |
| 3  | 54                                      |
| 4  | 53                                      |
| 5  | 51                                      |
| 6  | 34                                      |
| 7  | 33                                      |
| 8  | 22                                      |
| 9  | 18                                      |
| 10   | 12                                      |
| 11   | 9                                       |
| 12   | 7                                       |
| 13   | 7                                       |
| 14   | 5                                       |

Source: FY 84 HCFA Medicare Certified Hospice Cost Reports.

As was the case with dietary and drug expenditures, it is impossible to determine how much hospices spent only on Medicare patients. However, bereavement costs were a very small part of total hospice expenditure in FY84, averaging less than one percent across all four hospice types.

Payment equity and fairness: conclusion

Limited evidence from 36 Medicare-certified cost reports submitted in FY84, suggests that:

- FY84 routine home care payments rates covered costs for only half of the reporting certified hospices; adding \$10 to the daily rate raised payments above costs for about one-third of the hospices that had been "losers" under the lower rate.
- Payment rates for continuous home care and respite and general inpatient care, for the most part, did not cover hospices' costs.
- Providers' reported costs of outpatient drugs tended to exceed estimates that HCFA used to construct the routine and continuous home care payment rates. The outpatient drug copayment provision, which has not been implemented by certified hospices, seems unlikely either to deter Beneficiary utilization of outpatient drugs or to offer hospices a source of revenue that is worth the cost of collecting it.
- Dietary and nutritional counseling costs were not reported by most certified hospices.
- Bereavement costs, at an average of \$80 per patient, were less than 5 percent of total per patient costs in certified hospices.

These findings, from a small number of reporting hospices covering the first year of Benefit experience, suggest problems that may have to be addressed. However, they do not constitute an argument for a major overhaul of the Medicare Hospice Benefit payment system.

In addition, the past experience of hospices in delivering nutritional and bereavement support services shows disagreement among clinicians about what is appropriate care. As a result, many hospices have

not billed for some of these services. Among those that have, costs vary widely. It is difficult to argue from these findings that dietary and bereavement counseling services have been curtailed by the Benefit payment methodology, because similar patterns were observed under the more liberal cost-based system employed in the HCFA demonstration. While these early data offer no justification for an immediate change, either in the cost-sharing provision for outpatient drugs, in the method of covering all reimbursable services in inclusive per diem rates or in the exclusion of bereavement counseling from direct reimbursement, they also do not provide strong support for the current reimbursement system. Further experience under the Benefit may change providers' behavior, however, and evaluation of these issues will be included in the final report.

## CONCLUSION

During the first two years of the Medicare Hospice Benefit, fewer hospices than some had predicted sought and achieved certification; for those that were certified, there were further implementation delays caused by apprehensions of patients and families and by long lags in claims processing by intermediaries. The Benefit did not prove to be a financial drain on the Medicare Trust Fund; in fact, the data show that Benefit-reimbursed hospice care is still generally less expensive than conventional care. Yet critics charged that Medicare payment rates do not cover costs, and that the long run viability of the Benefit might be jeopardized by "unfair" payments to Medicare-certified hospices. FY84 cost report data from a small group of certified hospices lend some credence to these charges.

The issue for policy makers has to be whether or not these experiences prove that major changes in the Benefit should be made. If there are fundamental flaws in the program that discourage participation, then the logical response would be to identify these flaws and remove them. However, if the first two year's record merely reflects the normal growing pains of a radical new program, then tinkering with rate structures and certification standards could possibly do more harm than good.

As is often the case, the answer probably lies between these extreme positions. However, one thing should be clear, after a thorough reading of the evidence in this report. That is that information now available provides no grounds for a consensus on how to change the terms of the Benefit in any fundamental way. There are a number of reasons why this is true:

- early domination of the industry by provider-based hospices may be a temporary, start-up phenomenon that will disappear as Medicare certification becomes more common;

- the "bias" toward home care some see in the Hospice Benefit does not necessarily favor HHA-based hospices, because certification requirements call for coordinated provision of home and inpatient services;
- under certain assumptions the Benefit may have been a source of saving for Medicare in the first two years, but given changes in payment levels and legislation making the Benefit permanent, these savings estimates must be re-evaluated with FY86 data; preliminary evidence does suggest that freestanding and HHA-based programs do generate savings.
- evidence that payment rates are unfair to participating hospices, though troubling, is based on data from a small number of FY84 audited Medicare hospice cost reports; this issue needs to be addressed again with data from FY85 and 86.

#### Hospice Structure and Process Under the Benefit

Past research has shown the industry to be a mix of provider-affiliated and freestanding programs, numerically dominated by hospital-based hospices. Yet the hospices that were first certified have been overwhelmingly HHA-based and freestanding. Many observers see this as inevitable, arguing that the Benefit was structured to reward hospices that could provide services cost effectively in a home setting.

This observation is excessively simplistic, for two reasons. First, the hospice industry has been and remains both dynamic and innovative. In the early part of this decade, programs multiplied rapidly, and the variety of caring/treatment approaches included within the hospice concept ranged from the traditional medical model to nontraditional therapies. Some fear that the Benefit will push the industry in one direction, toward a more traditional "medical" structure with less freedom to innovate. Indeed, evidence from the JCAH survey shows that hospices certified in the first two years of the Benefit do adhere more closely to JCAH's own medical standards and criteria than the average noncertified hospice. However, data also suggest that penetration of the industry by Medicare-certified hospices has been too

limited thus far to have a decisive effect on development of the process of hospice care.

Second, certification requirements of the Benefit may change the criteria for success of hospices that elect the Benefit. The assumption that HHA-based hospices will prosper is based on the belief, encouraged by past research, that these programs have a comparative advantage in caring for patients at home. However, the certification standards that require direct or contract arrangement for all types of care put some hospital-based hospices in a relatively favorable position. Depending less on contracts for providing inpatient services, these programs should find the need to maintain close clinical and financial control over patient care more feasible than the average HHA-based program. Thus, the early evidence that hospital-based programs have rejected the Benefit program may be a temporary phenomenon; as other influences on hospice decision-making change, so may attitudes about certification.

#### Hospice Cost Effectiveness

Past evidence of significant hospice cost savings has reflected experiences of home-oriented models of hospice care, and generally applies principally to patients in the last one or two months of life. However, there are reasons to question both the validity of previous studies and the prospect for future savings. This report shows that some previous savings estimates may have been biased, because they may have been based on comparisons between the "wrong" kinds of hospice and conventional care patients. This Evaluation has sought to reduce this bias through more careful selection of comparison patients from the conventional care group.

Findings reported here suggest that hospice under the Benefit was no more expensive than conventional care. In fact, under certain assumptions,

real savings attributable to hospice may have been realized, particularly over the last month of life. As a final test, all three study years' data, including claims submitted under the new, higher 1986 hospice payment rates, will be analyzed for the final Evaluation Report.

As we noted earlier, terms of the Benefit itself may determine the organizational features of hospice that correlate with financial viability. Data show few hospices billing for inpatient and continuous home care; the high proportion of routine home care days suggests that Medicare expenditures under the Benefit will continue to be lower than the average both in conventional care and noncertified hospices. Of course, if this billing pattern represents a transitional unfamiliarity with the rules and policies of Medicare fiscal intermediaries, then in the future hospices may be more likely to prescribe and bill for more costly services as appropriate.

If hospices continue to provide over 80 percent of patient days at home, an important issue for the Medicare program may be maintenance of quality of care standards. Some research has suggested that services provided at home have less favorable outcomes, particularly in terms of pain control, than those provided in an inpatient setting. To preserve uniform quality standards, hospices must devote resources to training and monitoring primary caregivers. As the Benefit is now structured, quality standards must be developed and written in order for a hospice to be Medicare-certified, but no formal mechanism for review was prescribed in the Benefit regulations. Visits from representatives of state agencies (in states that license hospices) or from an accrediting body such as the JCAH represent the only external quality control mechanisms for hospice care currently in place.

### The Medicare Hospice Benefit Rate Structure

Proponents of hospice have concentrated on increasing the prospective per diem rates in the Benefit, rather than achieving fundamental changes in rate structure or certification requirements. The 1986 \$10 across-the-board increase in rates is not neutral with respect to the four categories: routine home care rates clearly increase most in percentage terms. However, this flat rate-increase initiative was based on the premise that major changes in the rate setting methodology would probably not have received much political support, given the scarcity of hard evidence regarding the fairness of the current system.

Next year's data, from the FY85 and 86 cost reports submitted by certified hospices to HCFA and from the HCFA-funded cost report/survey study of certified and noncertified hospices that is in progress, will provide a sound basis for evaluating payment fairness than the small number of reliable FY84 cost reports currently available. Nonetheless, the early findings in this area are cause for concern, suggesting that several certified hospices were unable to cover costs of services either under the FY84 rates or under the higher FY86 rates.



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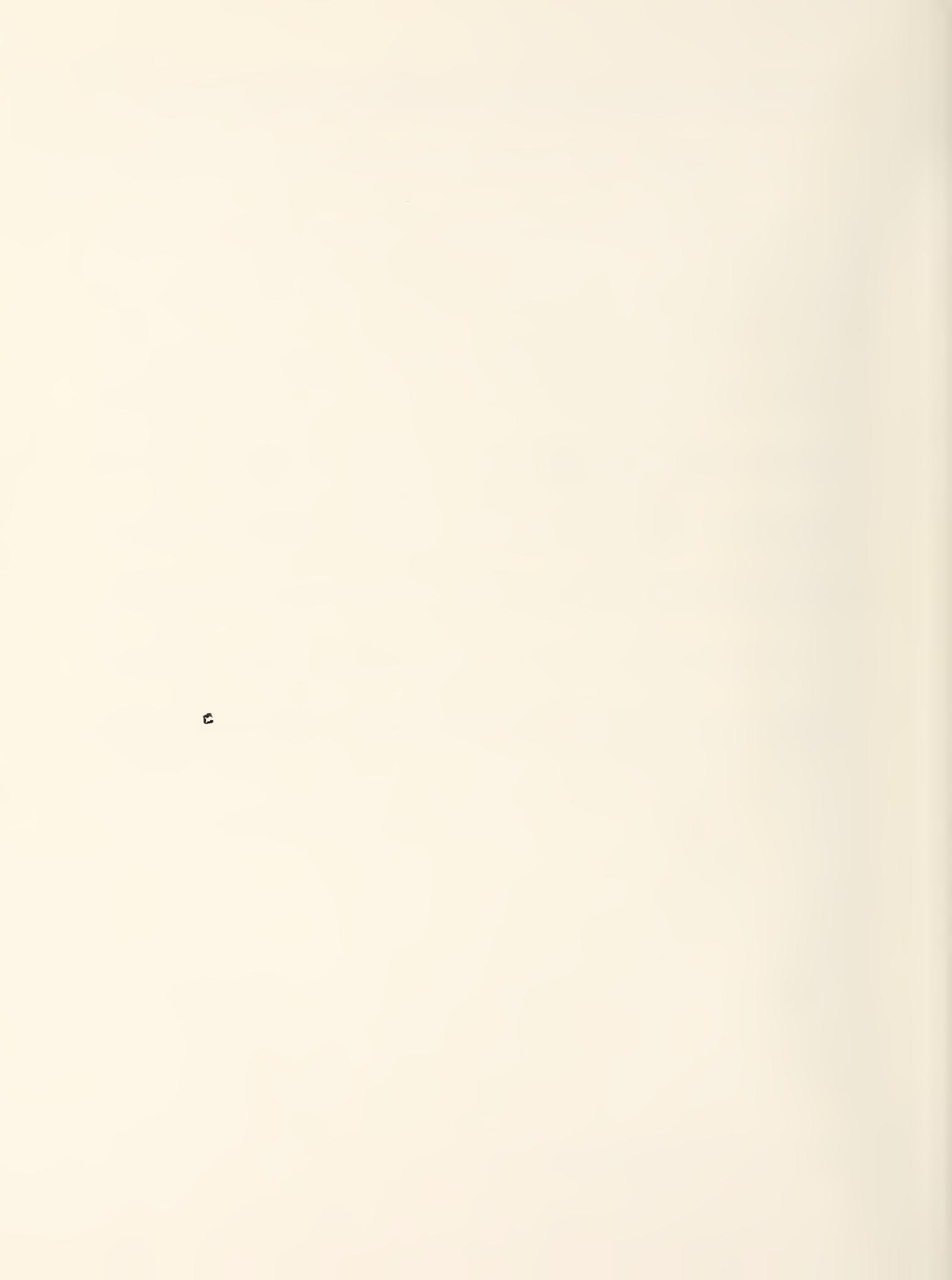
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